

**OLDER PEOPLE AND THE USE OF THE  
MENTAL HEALTH ACT (1983)**

**by**

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of the University of Birmingham for the degree of  
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**Institute of Applied Social Studies  
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## **ABSTRACT.**

This thesis explores the use of the Mental Health Act (MHA)(1983) with older people (65+) by providing a multi-perspective insight as expressed by those involved in the process. In particular, it focuses on the personal and social circumstances in which decisions to compulsorily detain older people are made. The thesis comprises two elements; one documentary, one qualitative. The documentary study was over a four-year period (2000-2003) gathering demographic data around various themes including numbers of older people detained, gender, age, diagnosis and the relevant section used to detain the older person under the MHA(1983) This provided an insight into the scale of the phenomenon.

Within the qualitative study, 58 semi-structured interviews were conducted providing fifteen case studies which were then thematically described and interpreted using Interpretative Phenomenological Analysis. Semi-structured 1:1 interviews were adopted to allow participants the opportunity to express their personal experience. The thesis concluded that at times, some older people and their caregivers became passive recipients of mental health services, mainly through power inequalities, particularly at the time of assessment and discharge.

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## **CONTENTS.**

<b><u>Introduction</u></b>	<b>1</b>
<b>Vignette – `Non – Compliance Leading to Compulsory Detention`.</b>	<b>1</b>
<b>Background to the Study.</b>	<b>2</b>
<b>Rationale for this Study.</b>	<b>2</b>
<b>Theoretical Context of the Thesis.</b>	<b>3</b>
<b>Key Concepts and the Structure of the Thesis.</b>	<b>4</b>
<b>The Research Questions - Aims and Objectives.</b>	<b>7</b>
<b>Role of Participants within the Study.</b>	<b>8</b>
 <b><u>Chapter 1</u></b>	
<b><u>Understanding Mental Health/Illness</u></b>	<b>10</b>
<b>Introduction</b>	<b>10</b>
<b>The Nature of the Problem: What is Mental Illness?</b>	<b>11</b>
<b>Social Construction of Mental Illness in Old Age – Challenging Stigma.</b>	<b>12</b>
<b>Social Creation of Old Age and Mental Illness</b>	<b>14</b>
<b>The Construction of Diagnostic Categories</b>	<b>17</b>
<b>Anti-Psychiatric Perspectives Relating to the Diagnosis</b>	<b>20</b>
<b>Implications of `Functional` Mental Health Problems in Later Life.</b>	<b>23</b>
<b>Depression in Old Age.</b>	<b>25</b>

<b>Professional Approach – Medicalisation and Medical Treatment of Depression in Older People.</b>	<b>28</b>
Response to Prescribed Medication – Problems of Polypharmacy	29
Electro-Convulsive Therapy (ECT)	32
Psychological Approach to Treatment	34
Interventionist Approach for Reducing Depression in Older People	35
<b>LifeCourse Approach to Understanding Mental Health Problems in Later Life.</b>	<b>36</b>
<b>Can Older People Recover from Mental Illness? The Recovery Model</b>	<b>38</b>
<b>Summary</b>	<b>40</b>

## **Chapter 2**

<b><u>Mental Health Policy and Legislation Applicable to Older People</u></b>	<b>43</b>
<b>Introduction</b>	<b>43</b>
<b>United Kingdom Policy Initiatives Concerning the Mental Health and Social Care of Older People</b>	<b>43</b>
The National Service Framework for Older People (2001)	46
<b>Implications for Practice; Working with Ambivalence</b>	<b>49</b>
<b>The Mental Health Act (1983) and MHA (Amendment) (2007)</b>	<b>52</b>
Policies Implemented in the Mental Health Act (2007) Possibly Impacting on the Experience of Some Older People	53
Criteria for Discharge from Hospital under a Community Treatment Order	55

<b>The Mental Health Act (1983) in Action!</b>	<b>57</b>
Comparisons of Admissions in England by Age and Gender (2008-2009)	57
<b>The Bournemouth Case (1998)</b>	<b>59</b>
<b>Mental Capacity Act (2005)</b>	<b>60</b>
<b>The Human Rights Act (1998)</b>	<b>65</b>
<b>Caregiver Policy and Legislation</b>	<b>67</b>
<b>Summary</b>	<b>70</b>

### **Chapter 3**

<b><u>A Multi-Perspective Analysis of Mental Illness, Assessment, Compulsory Detention and Outcomes Following Discharge from Hospital</u></b>	<b>72</b>
<b>Introduction</b>	<b>72</b>
<b>Multi – Perspective View of Mental Illness</b>	<b>73</b>
Professional View – Mental v Physical Disorder	73
Caregivers` View of Mental Illness – What Works?	75
Older Person`s View – The Need for Inclusion	78
<b>Personal and Social Circumstances of Older People Preceding Referral for a Mental Health Assessment</b>	<b>79</b>
<b>A Multi-Perspective View of the use of the MHA(1983,2007)</b>	<b>81</b>
The Professional Approach to Assessment.	81
A Caregiver`s Experience of Assessment - A `Struggle for Meaning`	82
The Older Person`s Experience of Assessment	86
<b>The Process of Compulsory Detention</b>	<b>88</b>

The Changing Roles of Mental Health Professionals	88
The Family/Caregiver Experience of Compulsory Detention	89
The Older Persons` Experience of Compulsory Detention	91
<b>Outcomes following Discharge from Hospital</b>	<b>92</b>
Professional Experience of the Discharge of Older People from Hospital Following Compulsory Detention	93
Discharge of the Older Person Back Home from Hospital – The Burden of Care?	94
The Experience of Family Caregivers - An Older Person's Admission into Care Following Discharge from Hospital	98
The Impact of Community Treatment Orders on Families	100
A Caregiver's Dilemma – An Older Person`s Non-Compliance with Medication	101
The Older Person's Experience of Receiving Care	104
<b>On the Contrary - Some Caregivers Report a Positive Experience!</b>	<b>106</b>
<b>Summary</b>	<b>107</b>
 <b><u>Chapter 4.</u></b>	
<b><u>Research Methodology</u></b>	<b>111</b>
<b>Introduction</b>	<b>111</b>
<b>Literature Review Search Strategy</b>	<b>111</b>
<b>Philosophical Underpinnings of the Study - Hermeneutic Phenomenology</b>	<b>114</b>
<b>Justification for Methodology</b>	<b>116</b>
<b>Ontological and Epistemological Position</b>	<b>117</b>



<b>Methods and Sources for Data Collection and Analysis of Documentary and Qualitative Studies</b>	<b>118</b>
Data Collection	118
One-to-One Interviews	121
Data Analysis - Interpretive Phenomenological Analysis	124
<b>The Triangulated Case Study Design Process</b>	<b>127</b>
<b>The Tensions and Potential Common Ground between the Two Qualitative Methodologies</b>	<b>128</b>
<b>The Ethics Requirement</b>	<b>130</b>
<b>Requirement for Informed Consent</b>	<b>133</b>
<b>Justifying the Sample Population</b>	<b>136</b>
<b>Pilot Study</b>	<b>139</b>
Pilot Study Data Analysis and Limitations	140
<b>Summary</b>	<b>142</b>
<b><u>Chapter 5</u></b>	
<b><u>Documentary Study – A Descriptive Profile of the Study Population</u></b>	<b>144</b>
<b>Introduction</b>	<b>144</b>
<b>Older People and Mental Illness</b>	<b>144</b>
<b>Family Members – The Caregivers</b>	<b>145</b>
<b>Data Analysis; Compulsory Detentions of Older People (2000-2003) at the Queen Elizabeth Psychiatric Hospital - Making Sense Of It All</b>	<b>147</b>
<b>The Gender and Age Imbalance</b>	<b>152</b>

<b>Gendered Comparison of the Living Circumstances of Older People Prior to Assessment and Following Discharge from Queen Elizabeth Psychiatric Hospital (2000- 2003)</b>	<b>154</b>
<b>Living Circumstances of Older People Prior to Assessment and Following Discharge from Hospital</b>	<b>155</b>
<b>Outcomes of Detention</b>	<b>156</b>
<b>Older People Living Alone at the Time of Assessment</b>	<b>158</b>
<b>Diagnosis at Time of Assessment</b>	<b>159</b>
<b>Summary</b>	<b>162</b>

## **Chapter 6**

<b><u>Multiple - Perspective Interpretations of Individual Experiences of Detention</u></b>	<b>163</b>
<b>Introduction</b>	<b>163</b>
<b>Harry's Experience</b>	<b>164</b>
Harry's Interpretation	164
Caregivers' Interpretation	166
Professional Interpretation	167
<b><i>Key Themes</i></b>	<b>169</b>
<b>Charlotte's Experience</b>	<b>169</b>
Charlotte's Interpretation	169
Steven's Interpretation	170
Professional Interpretation	171
<b><i>Key Themes</i></b>	<b>173</b>
<b>Michael's Experience</b>	<b>173</b>

Michael's Interpretation	173
Family Interpretation	174
Professional Interpretation	175
<b><i>Key Themes</i></b>	176
<b>Josephine`s Experience</b>	177
Josephine`s Interpretation	177
Caregiver`s Interpretation	178
Professional Interpretation	179
<b><i>Key Themes</i></b>	180
<b>Valerie's Experience</b>	180
Valerie's Interpretation	181
Caregiver Interpretation	182
Professional Interpretation	183
<b><i>Key Themes</i></b>	184
<b>George's Experience</b>	185
George's Interpretation	185
Professional Interpretation	186
<b><i>Key Themes</i></b>	187
<b>Katherine's Experience</b>	187
Katherine's Interpretation	188
Robert's Interpretation	188
Professional Interpretation	189

<b><i>Key Themes</i></b>	<b>191</b>
<b>Rita's Experience</b>	<b>191</b>
Rita's Interpretation	191
Caregiver's Interpretation	192
Professional Interpretation	194
<b><i>Key Themes</i></b>	<b>194</b>
<b>Helen's Experience</b>	<b>195</b>
Helen's Interpretation	195
Caregiver's Interpretation	196
Professional Interpretation	197
<b><i>Key Themes</i></b>	<b>198</b>
<b>Edward's Experience</b>	<b>198</b>
Caregiver's Interpretation	198
Professional Interpretation	200
<b><i>Key Themes</i></b>	<b>201</b>
<b>Agnes's Experience</b>	<b>201</b>
Agnes's Interpretation	202
Caregiver's Interpretation	202
Professional Interpretation	204
<b><i>Key Themes</i></b>	<b>205</b>
<b>John's Experience</b>	<b>205</b>
John's Interpretation	205
Caregiver's Interpretation	205

Professional Interpretation	208
<b><i>Key Themes</i></b>	<b>209</b>
<b>Alice's Experience</b>	<b>209</b>
Alice's Interpretation	210
Caregiver's Interpretation	211
Professional Interpretation	212
<b><i>Key Themes</i></b>	<b>213</b>
<b>Anne's Experience</b>	<b>214</b>
Anne's Interpretation	214
Robert's Interpretation	215
Professional Interpretation	216
<b><i>Key Themes</i></b>	<b>217</b>
<b>Joseph's Experience</b>	<b>217</b>
<b>Joseph's Interpretation</b>	<b>217</b>
Pamela's Interpretation	218
Professional Interpretation	219
<b><i>Key Themes</i></b>	<b>220</b>
<b><u>Chapter 7</u></b>	
<b><u>An Interpretative Phenomenological Analysis of an Older Person's Experience of the Use of the Mental Health Act (MHA)(1983)</u></b>	<b>221</b>
<b>Introduction</b>	<b>221</b>
<b>Barriers to Becoming a Mental Health Service User</b>	<b>223</b>
<b>Improve Knowledge – Early Intervention - Avoid Compulsion?</b>	<b>225</b>

Ageism as a Barrier to Appropriate Mental Health Services.	229
<b>Behaviour and Emotions at the Time of Assessment.</b>	<b>230</b>
Impact of Older Person's Behaviour on Families/Caregivers.	234
<b>Social Factors Leading to the Possible Compulsory Detention in Hospital of Older People with Mental Distress.</b>	<b>237</b>
Importance of Fulfilling and Quality Relationships.	238
The Effects of Social Isolation on Older People.	240
<b>Iatrogenic Effects of the Mental Health System.</b>	<b>242</b>
Power Issues Emerging During the Compulsory Detention Process.	242
Problems with Communication – Language, Discourse and Knowledge.	245
Tensions during Treatment in Hospital.	247
Power Inequality at Time of Discharge from Hospital.	248
<b>Disengagement from Services - Non-Compliance.</b>	<b>251</b>
Older People's Experiences of Medicalisation.	253
<b>Summary.</b>	<b>257</b>

## **Chapter 8**

<b><u>Reflections on My `Research Journey` - My Experience</u></b>	<b>263</b>
<b>Introduction</b>	<b>263</b>
<b>The Research Process - Issues Raised During the Research Process</b>	<b>264</b>
<b>The Early Days of my Study</b>	<b>264</b>
<b>Interview Dilemmas!</b>	<b>265</b>
<b>Who Holds the Power during Interviews – and Why?</b>	<b>266</b>

<b>So What Might of Helped?</b>	<b>269</b>
<b>A Change of Methodologies</b>	<b>269</b>
The Research Questions	<b>269</b>
Data Collection Strategy	<b>271</b>
Frames for Analysis	<b>273</b>
<b>Practitioner or Researcher</b>	<b>275</b>
<b>Summary</b>	<b>275</b>
<b><u>Conclusion</u></b>	<b>279</b>
<b>Justification for Mixed Methodology Approach for Data Collection</b>	<b>280</b>
<b>The Use of Interpretative Phenomenological Analysis (IPA)</b>	<b>283</b>
<b>The Research Questions</b>	<b>284</b>
<b>Research Findings</b>	<b>303</b>
<b>New Findings – Contribution to Knowledge</b>	<b>303</b>
<b>Recommendations for Future Research</b>	<b>305</b>
<b>Limitations to the Study</b>	<b>307</b>
<b><u>APPENDICES</u></b>	
Appendix 1	Relevant Sections of the Mental Health Act 1983 Referred to within this thesis
	<b>309</b>
Appendix 2	Letter of Invitation to Family Members
	<b>311</b>
Appendix 3	Information Sheet for Older People
	<b>312</b>

Appendix 4	Consent Form	314
Appendix 5	Introductory Letter for Doctors and ASWs	315
Appendix 6	Transcription: Harry's Story	316
<b>LIST OF REFERENCES.</b>		<b>318</b>



## **List of Figures.**

<b>Chapter 2.</b>		
2.1	Timetable and Progression of Mental Health Policy and Legislation	<b>44</b>
<b>Chapter 3.</b>		
3.1	Different Power Dynamics involved in relationships, Professional v Caregiver Approach. (Table adapted from the work of Jones, 2002)	<b>83</b>
3.2	Burdens experienced by some caregivers of older people with a mental illness. (Table informed from burden analysis by Lefley, 1996 and Wilkinson, 2001)	<b>96</b>
<b>Chapter 4.</b>		
4.1	Relationship between Ontology, Epistemology, Methodology Methods and Sources. (Adapted from Grix, 2001)	<b>117</b>
<b>Chapter 5.</b>		
5.1	Gender Comparisons of Compulsory Detentions of Older People 65 and over in SBMHT (2000-2003)	<b>152</b>
5.2	Gender and age groups of older people detained at the Queen Elizabeth Psychiatric Hospital (2000-2003)	<b>153</b>
<b>Chapter 7.</b>		
7.1	Themes/Sub-Themes raised by participants during the narrative interviews.	<b>222</b>

## **List of Tables**

### **Chapter 1.**

- 1.1** Prevalence of depression in England in 2000.  
(The British Journal of Psychiatry (2003) 183: 514-519) **26**

### **Chapter 2.**

- 2.1** Numbers of hospital inpatients across all age groups in  
England during the year 2008-2009 by age and gender.  
(Source: Health and Social Care Information Centre, Mental  
Health Minimum Dataset (MHMDs) Annual Returns) **58**

### **Chapter 4.**

- 4.1** Keywords used in Literature Review Search Strategy **113**

### **Chapter 5.**

- 5.1** Total number of formal detentions of older people within the  
Queen Elizabeth psychiatric hospital. (SBMHT) (2000-2003) **148**
- 5.2** Yearly comparison of the main sections of the MHA (1983)  
used to detain older people within the Queen Elizabeth  
psychiatric hospital (SBMHT) (2000-2003) **149**
- 5.3** Where older men and women were living at the time of  
their assessment and, discharged to, following detention  
at Queen Elizabeth psychiatric hospital (SBMHT) **155**
- 5.4** Household support available to those older people living  
in warden accommodation or their own homes prior to  
their assessment (The most relevant categories) **159**
- 5.5** Diagnosis of older people following assessment leading  
to compulsory detention at Queen Elizabeth  
psychiatric hospital within SBMHT (2000-2003) **160**

## **Introduction.**

The principle aim of this study was to explore the experiences of older people, (65+) who had been compulsorily detained under the Mental Health Act (MHA) (1983) In relation to the legal and historical context of this study, the research was conducted prior to changes in mental health legislation, in particular, the Mental Health (Amendment) Act (MHA) (2007) Consequently, reference will be made throughout the thesis to aspects of the MHA (1983) Some further clarification is required. Within this study, mental distress will be used to identify that time before any diagnosis has been made – whereupon, I will refer to mental illness/disorder.

## **Vignette – ‘Non – Compliance Leading to Compulsory Detention’.**

Michael is 82 and, although physically well, has a long mental health history – resulting in several episodes where compulsory detention in hospital was the outcome. According to Michael, he was not mentally ill and should not be in hospital. One of his identified problems was non-compliance with prescribed medication which led to him becoming highly aggressive, both verbally and physically. During his stay in hospital, his illness was stabilised with prescribed medication although on discharge, a decision was made to seek alternative accommodation to where he was admitted from for two reasons – the housing association refused to let him return to his previous home because of the trouble he had caused and staff considered it best if he was admitted to a care home where his intake of medication could be effectively dispensed and monitored.

### **Background to the Study.**

This research project was funded by a studentship from the Institute of Applied Social Studies at the University of Birmingham and the South Birmingham Mental Health Trust (SBMHT) in 2002. The value of this study was emphasised in the proposal, stating analysis of data gathered could contribute to an improved quality of service for older people. The roots of this research lay in a previous study conducted by Barnes et al (1990) which monitored all work arising from the use of the MHA (1983) referred to 42 social service departments during a 12 month period. The data collected for that study allowed analysis of people, across all age groups, who were considered for possible detention under the MHA (1983). Conclusions were drawn highlighting not just who was being considered for detention, but also the rates at which different groups within the studied population were being admitted to hospital. One such group was older people and concern was expressed relating to the high percentage referred for assessment.

### **Rationale for this Study.**

Although there has been previous research exploring the circumstances of people with a mental illness including older people (Barnes, et al 1990; Nolan, et al 2001; Rogers and Pilgrim 2003) there has been limited research that has specifically focused on the perspective of those subject to the MHA (1983) of whatever age. Furthermore, the absence of research which focuses on the subjective impact compulsory detention has on caregivers of older people is both lacking and important. Hence, this thesis brings together a range of multi-perspectives that may

be useful in understanding, not simply mental illness, but also the social and personal issues that may connect with it. It was vital to capture the perspectives of those people with direct personal experience of living with, or working alongside older people with a mental illness, because they had a valid contribution to make.

A contributing factor supporting my interest in this area has been my employment as a Mental Health Act (Hospital) Manager with Merseycare which has provided me with a valuable insight into the use of the Act across all age groups, but at times with older people. This includes the use of Compulsory Treatment Orders introduced within the Mental Health (Amendment) Act (2007) I have also worked as a support worker, which has entailed supporting people, again, across all age groups, but including older people, with either a physical or mental disorder. During the course of my employment I identified, what I considered to be, several ageist issues. On several occasions, some work colleagues implied the older person's condition should be expected 'at their age'. Similarly, some family members often put the older person's condition down to 'them getting on'. Occurrences similar to these ignited my interest in exploring further, the stigma and stereotypical attitude that surrounds mental illness and older people.

### **Theoretical Context of the Thesis.**

Ageing is an individual experience, although there are a number of common theories in accounts of growing older. For example, old age is often encountered as a time of multiple losses, requiring adaptation to possible new situations and environments. Some individual experiences of mental illness in later life may be

unique but there may be some experiences that are common to those with particular mental health needs. An understanding of the range of these experiences is essential in order to support older people and their families effectively. There are different ways of viewing ageism. Some may consider it an issue specifically tied to old age, or it may be considered as having roots in earlier stages of life. Some frameworks for ageism may be more expansive than others, endeavouring to understand not only potential negative consequences of attitudes, behaviours, policies and practices for the lives of older people, but how systems respond to the people that informally and formally support them.

The process of ageing involves a combination of biological, psychological and social changes which may be quite challenging and can be compounded by the presence of a mental illness, creating what has been termed 'double jeopardy' (Age Concern, 2006) However, poor mental health is not a normal and inevitable part of the ageing process as the majority of older people enjoy good mental health and continue to make a valuable contribution to society. Evidence about the factors that affect mental health and well-being has increased in recent years. We now know much more, for example, about the link between certain social circumstances of older people including isolation, poverty and mental illness – which may lead to compulsory detention in hospital.

### **Key Concepts and the Structure of the Thesis.**

Mental health is a highly contentious concept. The key concepts within this thesis are examined through a multidisciplinary lens, drawing together a plurality of

overlapping perspectives from professionals, older people and family/caregivers that reflect the complexity and diversity of experience based on factors including age, personal biography, emotions and family and social circumstances. The principal aim of conducting the literature review was to `set the scene` by examining the contextual background to help engage with my research questions. Debates around the reliability of diagnoses and anti-psychiatric and social perspectives of mental illnesses are all part of the context of understanding its contested nature.

The focus for Chapter one is the experience of older people – particularly the implications of `functional` mental health difficulties in old age. According to a report from the Institute for Public Policy Research (2008) urgent action needs to be taken to curb a decline in mental health and wellbeing amongst people 65 and over. At that time, it was estimated that 2.4 million older people in the United Kingdom had depression which impaired on their quality of life. Significant contributing factors included older people living alone, with a strong association between levels of deprivation, mainly poverty and emotional wellbeing. Additionally the report stated that in 2007- 8, 2.5 million people over the age of 65 were living in poverty – up 300,000 on the previous year.

Chapter 2 discusses the application of mental health legislation and the impact of its use with older people. This will include policy and legislation that was relevant at the time I conducted my fieldwork during 2003. Chapter 3 provides a multiple-perspective account of the process of assessment, treatment during the older

person's stay in hospital and outcomes following discharge. According to Fulford (2004) central to the work on values is the notion that power and knowledge are inextricably linked and suggests multidisciplinary mental health practice must acknowledge and respect a plurality of knowledge bases – with particular primacy being given to the views of service users. Chapter 4 introduces and explains the methodology used within this study and, in particular, both the tensions and potential common ground between the two qualitative methodologies adopted – Interpretative Phenomenological Analysis (IPA) and a Case Study Design. IPA researchers are especially interested in what happens when the everyday flow of lived experience takes on a particular significance for people, usually when something important has happened in their lives. Chapter 5 provides a descriptive profile of the study population from which the qualitative sample was drawn

At this juncture, I am moving to the thesis `findings` to examine what my empirical evidence revealed. Consequently, Chapter 6 presents 15 case studies of the narrative interviews I conducted, to help gather an authentic understanding of the multiple perspectives of the older person's experience of assessment, compulsory detention and discharge. Chapter 7 is a cross-case analysis interpreting the commonalities and differences between the different perspectives gathered and analysed in relation to the relevant literature. Chapter 8 is my personal reflection on the research journey considering issues I was faced with and highlighting things I might do differently if was starting again. The conclusion addresses individually the



research questions and in doing so, suggests further areas for future research, while reflecting on the methods used.

### **The Research Questions - Aims and Objectives.**

The research questions and objectives are expounded below. The overall aim was to consider different perspectives from different sources to help present a bigger picture and simultaneously help achieve deeper levels of knowledge and understanding. Hence, the research questions were:

#### **1) What are the social and personal antecedents of older people leading to compulsory detention in hospital?**

What are the signs, the `triggers` that may alert family members to the possible onset of mental disorder in an older person? Is there any noticeable difference in an older person's behaviour prior to the onset of mental distress? If an older person has become isolated possibly through living alone, effective and timely interventions may be needed to help maintain mental health in old age. Data was gathered from one-to-one interviews with older people, caregivers and professionals.

#### **2) How does power operate between different participants at the time of assessment and while detained in hospital?**

The possession of power implies a one-sided view of a particular phenomenon for example a mental health assessment. Power is often identified with particular interests, often representing dominant individuals or institutions, who are able to exercise it to secure social order and discipline, but also, importantly, to offer safeguards and protection to both the public and vulnerable groups, for example

older people. However, if one group holds all the power and knowledge, what is the impact on relationships between those involved? Data was gathered from one-to-one interviews with older people, caregivers and professionals.

**3) What are the outcomes following discharge from hospital for older people?**

An older person's personal and social circumstances prior to assessment may have contributed to their mental distress. If these circumstances are addressed the older person may be allowed to return home following discharge from hospital which may support the efficacy of detention. However, the opposite could also be true, that is, the older person may be discharged back home without any change to their social circumstances, which may result in re-admission to hospital. Data was gathered from all participants during the interview process.

**4) What is the 'lived' experience of compulsory detention for older people, caregivers and professionals?**

Within the qualitative element of this study, I have explored how the experience of compulsory detention under the MHA (1983) was interpreted by all participants. At the time of assessment, there were several occasions when events described by the older person differed from the interpretation of the same event by the caregiver and the professionals involved. Data was gathered from all participants during the interview process.

**Role of Participants within the Study.**

The originality of this research study and hence my contribution to knowledge lays within the qualitative element, in particular analysis of the multiple perspectives.

This element of the study conducted a total of 58 one-to-one semi-structured interviews; 14 with older people who had been detained under the MHA (1983) and 14 with caregivers to explore the impact detention had on their lives. Additionally, there were 15 interviews with Consultants/ General Practitioners and 15 with Approved Social Workers (ASWs) which produced 15 case studies. The multiple perspective approach produced varied responses to the assessment and detention experience.

So why involve older people with a mental illness in research? Walker (2007) argues strongly that the main reason is a matter of human rights. Like any human research subjects, older people have a right to be consulted about research that is conducted about them. The results of this research study are enriched by incorporating older people's interpretations and experiences of compulsory detention in hospital. Walker (2007) concludes that if researchers want to produce findings that contribute to the quality of life of older people, or indeed, to the quality of services they use, then it is essential to involve them so they can contribute their own understandings about ageing and service use which can often be far removed from that of academic researchers and medical professionals. Walker's (2007) analysis underpins and supports the methodological approach adopted within the qualitative element of this study.

## ***Chapter 1.***

### **Understanding Mental Health/Illness.**

#### **Introduction.**

Mental health in later life is influenced by a complex set of biological, psychological and social interactions with the majority of studies of mental health and old age predominantly rooted within a clinical framework, with relatively little emerging from a social perspective (Pilgrim 2005) Initially, this chapter will consider the debate around mental illness before examining the social construction/creation of mental illness in old age, including the `labelling` process. The construction of diagnostic categories will be discussed through the use of the Diagnostic and Statistical Manual of Mental Disorders (DSM I (1952), DSM II (1968), DSM III (1980), DSM IV (1994), and DSM IV-TR (2000) Additionally, this chapter will consider the implications of `functional` mental health difficulties in older age, particularly depression, with an added emphasis on the adoption of a lifecourse approach to understanding mental health problems in later life. Material for this review is quite diverse and has been gathered from clinical, social, legislative and policy sources. Defining mental health/distress/illness/disorder can mean different things to different people so some clarification is required at this point. Mental health problems, mental health, mental ill-health, mental distress, mental illness and mental disorder have been used quite `loosely` and with a comparable lack of precision – the latter two most often interchangeably. As mentioned earlier, I will refer to mental distress as that time preceding diagnosis, and the term mental illness/disorder will be used post diagnosis.

## **The Nature of the Problem; What is Mental Health/Illness?**

Pilgrim (2005) stated mental health and mental illness are determined by multiple and interacting social, psychological and biological factors – similar to health and illness in general. Pilgrim (2005) continued stating the term `mental health` can be used positively to indicate a state of psychological wellbeing, while `mental illness` reflects the breakdown of emotional order. Similarly, the World Health Organisation (WHO) (2009) and the Mental Health Foundation (1997) conceptualise good mental health as a state of wellbeing, in which people realise their own abilities, can cope with the `normal` stresses of life, can work productively while able to make a contribution within their community. The WHO (2009) claim the essential dimension is contained within their constitution suggesting health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity.

However, Marshall (2004) states that mental illness is an extremely controversial topic asking

... what is mental illness? Does it really exist? Are we referring to something of the mind, of the brain, or of the whole person? Is it an illness? What is an illness anyway? Or is it a cluster of random symptoms and behaviours? Or one point on a wide continuum of possible human experiences?

(Marshall, 2004:137)

To clarify matters, the Mental Health Act (MHA) (2007:7) defines mental disorder as “any disorder or disability of the mind” and, in doing so, changes the way the MHA (1983) defined mental disorder. The intention is to provide a single definition throughout the Mental Health (Amendment) Act (2007) by abolishing any other

references to other categories of disorder. Pilgrim (2005) concludes mental disorder is not a single disease, but rather a broad collection of various experiences that can seriously impact upon an individual's ability to cope with everyday life, but conceptualised in different ways. The notion of biological causality remains a major orienting principle in efforts to understand the nature of mental illness. A useful convention was adopted, however, by segregating 'organic' from 'functional' mental disorders. This dichotomy is based upon an aetiological distinction - the presence or absence of a biological abnormality or dysfunction that fully accounts for the condition. Specific examples include anxiety, depression, dementia, and schizophrenia. Nonetheless, the two broad concepts often associated with mental ill health are 'disorder', implying a deviation from the 'norm', and 'illness' which implies analogy with physical illness. There exist several theoretical assumptions made by some sections of society relating to old age and mental illness and will be discussed next.

#### Social Construction of Mental Illness in Old Age - Challenging Stigma.

Throughout this section, my interpretation of social construction will be underpinned by the work of Scheff (1966) who challenged common perceptions of mental illness claiming it is manifested solely as a result of societal influence, because it is often the rules defined by society that create the deviance by which individuals are labelled. Scheff (1966) claimed that once a person is labelled as mentally ill, they may find it difficult to become de-labelled. Lemert (1981) developed the concept of primary and secondary deviance as a way of explaining

the process of labelling, stating primary deviance refers to any general deviance before the deviant is labelled, whereas secondary deviance is any action that takes place after the primary deviance as a reaction to society. According to Lemert (1981) this perceived association could impact on the lives of people who may have restricted social networks not simply because of their mental illness, but quite often, as a result of the societal responses to their perceived illness - a theory that could be applied to some older people in this study.

A psychiatric label can also generate self-stigma referring to the shame and self-directed prejudice experienced by the individual, who applies negative stereotypes toward her/himself (Corrigan, 2007) Self-stigma has also been associated with a host of negative outcomes including depression, lowered self-esteem, social isolation, and reluctance to seek help (e.g., Corrigan, Watson and Barr, 2006) Furthermore several studies have documented the variable and complex way in which adults react to being labelled by professionals. Many older patients do not accept the psychiatric diagnoses ascribed to them, often preferring alternative, less pathological explanations for problems (Camp, Finlay and Lyons, 2002; Van Voorhees, Fogel and Houston, 2005) In other words, many patients who are labelled do not self-label or attribute their problems to mental illness/disorder. For example, O'Mahony (1982) found that adult psychiatric inpatients agreed with negative stereotypes concerning mentally ill people in general, but denied that these stereotypes represented them. However, it is important to note that labels can also have positive effects that partially offset the stigmatizing and demoralizing

impact of the label. Some patients describe relief in having a label that can explain psychological symptoms, validate their experiences and guide them in knowing what to expect and how to cope (Hayne, 2003) According to Salzman (1997) stigma around old age is often linked to confusion, dependence and inevitable decline - possible antecedents to mental distress, but argues these `conditions` should not be considered a natural part of the ageing process and furthermore, older people should not be `labelled` in a way that implies reduced competence. Walker and Maltby (1997) state that whilst it cannot be denied there is an increasing risk of chronic illness and disability associated with old age, it would not be true to presume that *all* older people will become dependent on others; nor can the perception that old age is itself an illness be justified. Furthermore, they argue that, from an older person's perspective, there is a danger they may attempt to cope with the exclusion and stigma caused by their mental distress because they perceive the `symptoms` to be age related, rather than a treatable condition.

#### Social Creation of Old Age and Mental Illness.

The interplay between social and environmental factors may have created a further theoretical framework through which particular experiences of old age and mental illness may be viewed and consequently, my interpretation differs from the analysis of social construction theory. The emphasis within this perspective is recognising the relationship between old age, mental illness and social disadvantage. Rogers and Pilgrim (2003) confirm that apart from biological and psychological factors, there are a variety of social factors for example; age, poverty and gender which are



often associated with mental illness in older people and identify these issues as important factors which can create social disadvantage. Rogers and Pilgrim (2003) suggest that displacement from the labour market may leave an older person with a reduced income, with the type of employment previously held impacting on the level of accumulated pension. Those older people who have previously held high status jobs may have planned well for the future, but those who have endured periods of low-paid jobs and/or long periods of unemployment may be reliant on a residual state pension. Rogers and Pilgrim (2003) conclude that the socio-economic impact of poverty on an older person during their lifecourse can directly affect their social networks and consequently, lead to an increased risk of personal isolation and exclusion. However, poverty is not simply about money but may also include poverty of family and community life. Some older people need to be surrounded by the `natural` support of family and friends in the community. As Jones (2002) claims, family and social relationships are extremely important and are somehow fundamental to mental health, but if absent, can lead to a form of exclusion and disengagement from society.

Phillipson (1998) states that ageing has been seen as an increasing problem since the birth of the welfare state, epitomised by the need for enforced retirement. The outcome is a homogenous group of elderly people with a growing dependency. Phillipson (1998) argues old age can have the effect of amplifying poverty, suggesting that if an older person has experienced low levels of income throughout their lives, the onset of old age can often make the situation worse, possibly

plunging them into poverty. However, those older people who have enjoyed a relatively good standard of living in their lives might also find themselves in financial difficulties if they have not made adequate pension provision. Vincent and Phillipson (2006) suggest there is an inequality associated with a pension system that is directly linked to past employment and earnings histories, with some women being particularly disadvantaged by such a system because of their inability to work because of caregiving responsibilities. According to Vincent and Phillipson (2006) women are the principal caregivers and consequently, unpaid caregiving should be a qualifying criterion for state pension entitlement.

However, whilst not denying the need for a system that ensures financial security for all in old age, a revised state pension scheme on its own, aimed at resolving inequalities in retirement when they may have existed throughout the lifecourse may be difficult to achieve. Townsend (1986) referred to the `structured dependency` of older people, arguing that the problems they experience within society owe more to social, political and economic factors than to the natural process of ageing. For example, the concepts of retirement, pensionable status and institutional residence have been developed in ways which have created and reinforced the social dependency of older people. Hence, the social creation of old age may not stem from the accumulation of years per se, but rather from social arrangements, particularly economic, that has placed older people in a marginal position within society. As Townsend (1986) concluded, although `society` may recognise the `lines` between young and old and madness and sanity, it may not

recognise that the `lines` drawn may have been socially created - albeit unintentionally.

### **The Construction of Diagnostic Categories.**

Mental `illness` is not a unitary phenomenon - rather it can take many forms just as physical illnesses do, which may make diagnosis difficult (Matthews, 1999)

Attempts to address the problems of psychiatric diagnosis have focused on attempts to develop reliable diagnostic criteria. There are two accepted international systems for the classification of mental disorders; the World Health Organisation's International Classification of Disease (WHO ICD-10) and the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, (DSM IV-TR). Because of word constraints I will discuss the latter approach only - psychiatrists may prefer one over the other and that is at their own professional discretion but most use both.

Psychiatric practice in the first part of the twentieth century did not place any great emphasis on particular diagnostic categories. The first official DSM appeared in 1952 but specific diagnostic entities had a limited role and according to Horwitz (2002) conceived of symptoms as reflections of broad underlying dynamic conditions or as reactions to difficult life problems. Several authors, including Kirk and Hutchins (1992) and Horwitz (2002) state DSM-I and DSM-II made little effort to provide elaborate classification schemes, particularly the early DSMs (1952; 1968) which were not very clear because they were not based on any clear indicators to aid with diagnosis. As a result, one of the limitations to this view of

mental disorder was that it poorly separated healthy people from mentally ill people. Because of this observed inconsistency, Horwitz (2002) stated the early DSM process became contested and led to various critiques both in principle and in its application. Far from being a scientific categorisation of disorder, Horwitz (2002) concluded that psychiatric diagnosis became an arbitrary procedure determined by political and social processes to meet mostly social and economic ends. In contrast, Horwitz (2002) states DSM-III (1980) emphasised categories of illness rather than indistinct boundaries between normal and abnormal behaviour.

The distinctive feature of DSM-III was its use of categorical symptom-based diagnosis to define mental disorder. Horwitz (2002) claims prior to the introduction of DSM-III, psychiatrists tended to diagnose mental disorders without using any standardised criteria - consequently two psychiatrists assessing the same patient may disagree completely on diagnosis. According to Goodwin (1997) the DSM-III imported a model from medicine where diagnosis was the keystone of medical practice and clinical research, and as a consequence, psychiatry reorganised itself from a discipline where diagnosis played a marginal role to one where it became the basis of the speciality. Psychiatry shed one particular paradigm and adopted an entirely new system of classification. DSM-IV (1994) focuses on evidence based research to aid with the classification of mental distress, by providing the means by which current best evidence from research can be applied to the diagnostic process. In addition to the diagnostic criteria, information relating to prevalence, familial patterns, age, gender and cultural issues of disorders is provided to help

clinicians understand how to apply the criteria (DSM, 1994) which places its application within a more social perspective, rather than the previously preferred medical model. One of the aims of the DSM-IV was to involve people from a broad array of professional disciplines, as it was deemed important to represent a wide breadth and diversity of people and expertise as possible. There are five diagnostic axes specified within DSM-IV-TR – a revised edition published in the year 2000. It contains five diagnostic Axes described below;

- **Axis I** - Clinical disorders, including major mental disorders and learning disorders.
- **Axis II** - Personality disorders and mental retardation (although developmental disorders, such as Autism, were coded on Axis 11 in the previous edition, these disorders are included on Axis 1.
- **Axis III** - Acute medical conditions and physical disorders.
- **Axis IV** - Psychosocial and environmental factors contributing to the disorder.
- **Axis V** - Global Assessment of Functioning or Children's Global Assessment Scale for children and teens under the age of 18.

Axis V focuses on a `Global Assessment of Functioning and measures the level of functioning on a scale 1-100, which allows the doctor to rate the person's general level of functioning and aids the development of a treatment plan and also evaluates treatment progress. One of the specialised global scales is the Social and Occupational Functioning Assessment Scale which may be of particular relevance to older people. The `core` symptoms of a mental illness can have a profound affect on both the older person and, the family caregiver's quality of life and may significantly interfere with their daily functioning depriving them of the

ability to take pleasure in activities or relationships they had previously enjoyed – areas considered at the time of assessment.

#### Anti-Psychiatric Perspectives Relating to Diagnosis.

As an approach to the diagnosis of mental illness, the DSM process has not gone un-criticised. According to Eriksen and Kress (2005) despite the staying power and benefits of the DSM process, it does have limitations. Several are applicable to this study and could possibly impact on the experience of some older people. For example, Eriksen and Kress (2005) suggest the DSM diagnostic categories can lead people to accept a self-fulfilling prophecy that their situation is hopeless and that they are `sick`, which links with Walker and Marty's (1997) analysis that older people accept their `illness` as age-related, rather than a condition that can be treated. As early as the 1960s, the validity of psychiatry's central concept of mental illness was challenged, particularly by a group referred to as the `anti-psychiatry movement`, who contended, in Szasz's terms, that mental illness is a `myth` (Szasz 1961) and concluded that psychiatry is an extension of the state used for controlling non-conformists and furthermore, psychiatric `labels` via diagnosis only serve the needs of professionals and dominant groups rather than the needs of the patients. Scheff (1966) referred to a `societal reaction` tradition, which described mental illness as a social role owing less to the nature of the displayed symptoms themselves and more to the reaction of others to them. Hence, if an older person's behaviour fails to meet the expectations of society and other explanations of their

behaviour fail, they may be labelled 'mentally ill', which can, in extremis, result in removal of their liberty through compulsory detention.

Rosenhan (1973) questions the categorisation of mental illness, arguing that psychiatric diagnoses are in the minds of the observers and are not valid summaries of characteristics displayed by the observed. According to Rosenhan, (1973) professionals believe that when individuals present with symptoms, they can be categorised through the application of diagnostic procedures and, implicitly, the sane can be distinguished from the insane. Rosenhan's (1973) conclusions were drawn following an experiment where eight people gained secret admission to twelve different hospitals, by complaining they were 'hearing voices', which in some patients, is a recognised symptom of schizophrenia. Upon admission to the psychiatric ward the 'pseudo-patient' ceased simulating any symptoms of abnormality. However, despite the public show of sanity, the pseudo-patients were never detected, (except by other patients) and all, except in one case, were diagnosed as schizophrenic and were eventually discharged with a diagnosis of schizophrenia 'in remission'. Rosenhan (1973) concluded that this failure to correctly diagnose the pseudo-patients spoke volumes about traditions within psychiatric hospitals particularly the use of diagnostic procedures.

The reliability and validity of the DSM was also questioned by Boyle (2002), who suggested that for science to grow it is essential that the problems we wish to tackle are real. That is, in order to make progress toward problem resolution in the real world, we need to be sure that a concept or entity related to a problem exists

and that we can consistently agree on how to identify it. For example, if we wish to explain an occurrence of violent and threatening behavior for which the perpetrator offers an explanation and so calling the occurrence the result of the DSM-defined mental disorder schizophrenia, then we would want to make sure that this disorder actually exists (Boyle, 2002) Kirk and Kutchins (1992) strongly critiqued the reliability of DSM mental disorders claiming the diagnostic reliability of the DSM to be significantly flawed in all three of the modern versions (DSM-III, -III-R, and -IV), each of which were specifically designed to address the problems of reliability found in earlier versions. According to Bentall (2004:21) formal psychiatric classification and diagnostic systems are subject to the limitations of the methods used to create them - 'psychiatric diagnosis is not dissimilar to astrology: both systems attempt to tell us something about people and to predict what will happen to them in the future, and both fail miserably'. In practice, patients frequently fail to 'fit' into a particular category or, conversely, may fall into several. The categorical 'present or absent' approach to diagnosis encourages a polarised understanding of mental health rather than one which recognises human experience as richly diverse and fluid, and better represented as a continuum. More significant, perhaps, is the criticism that rigid adherence to formal classification and diagnostic systems 'encourages unthinking practice and an impersonal approach' (Double, 2001: 43)



### **Implications of 'Functional' Mental Health Problems in Later Life.**

According to Mann et al (2000) the term 'functional mental illness' is a generic term describing disorders that are not associated with a biological cause, although biological factors can play a part in many of these conditions. In older people, the most prevalent functional illness is depression. Less common, but also present, are other psychiatric illnesses, for example, schizophrenia, paraphrenia, schizo-affective disorder and bipolar disorder, previously referred to as manic depressive disorder. Mental illness in old age is very common across all care settings, but is often unrecognised due to the nature of the symptoms and also because many older people live alone. Depression in people aged 65 and over is especially under-diagnosed and is particularly true of residents in care homes (Mann et al 2000) Rates of depressive illness in older people vary between 1 and 3%, but 10-15% of older people have depressive symptoms but unlike dementia, there is no obvious age-related increase in prevalence. For example, people in their 90's have lower rates of depression than people in their 60's and 70's (Burns et al, 2002)

A Department of Health (2008a) report focuses on age discrimination within mental health services. Available literature, both academic and policy-related and data obtained from interviews conducted with senior and middle managers in eight organisations highlighted the perceived extent of age discrimination. Problems undertaking intervention work with older people experiencing mental health problems, particularly anxiety and depression were identified. The Age Concern Inquiry (2007) highlighted challenges in both primary and secondary care. Within

community services, research has shown that only a third of older people with depression discuss their mental health with their doctor and less than half of them are treated. General Practitioners are key to accessing secondary or specialist care but only 6% of older people with depression receive specialist mental health care. Significant unmet needs among people over 65 suffering low level functional mental health problems were also identified. The services were structured such that if a person had not been in receipt of a mental health service prior to the age of 65 for functional mental health problems they would be less likely to receive a service post-65 because their problems would be less likely to be identified. Additionally, services available to older people were stated to be institution-based because those that may have enabled them to remain in the community were problematic and in some cases, some older people were entering residential and nursing care settings unnecessarily.

A further problem related to information sharing. Neither staff nor service users of older people's mental health teams were aware of some adult services. For example, in one organisation the older people's mental health service was not aware of the services provided by an Assertive Outreach Team, which is located within the adult mental health service, and thus older service users were not able to access these supports. Age Concern (2007) also noted that older people who take their own lives have diagnosable mental health problems but only a small minority are in contact with specialist mental health and suggest home-based assessments may increase the proportion of patients and carers seen. In 2000,

only 44% of the areas visited for an Audit Commission study had specialist multidisciplinary teams for older people and only one in seven had home care staff trained in mental health issues who were consistently available (Audit Commission, 2000) As mentioned earlier, the most prevalent functional illness in older people is depression and will be discussed in more detail in the following section.

### **Depression in Old Age.**

According to Anderson (2001) with a prevalence of 10-15% among the UK population 65 and over, depression is two to three times more common than dementia. Stokes (2000) referred to depression as the `silent epidemic` - a clinical phenomenon often unnoticed behind a barrier of social distance and isolation, although emphasising depression can, and indeed very often does, exist separately from dementia. Murphy (1992) provided an insight into the origins of depression in older people, reporting that life experiences are major factors leading to depression, not specifically one stressful event, but rather a culmination of mostly minor life events. Those older people who appeared to be at greatest risk are those without close friends or family. By virtue of their age, some older people will have experienced more stressful events in their life compared to a younger person, for example, serious illness or bereavement. The most prominent observation from Table 1.1 is the over-representation of women in all age groups which underlines Ussher's (1991) study which highlighted the gender differences that exists within mental health services which she described as a misogyny and consequently at the root of the imbalance observed below. At some point in their

lives, one in four women and one in ten men across their respective life spans in the UK will experience a period of depression serious enough to require treatment.

Age (years)	Number of cases		Total <sup>2</sup>	
	Male	Female		(%)
16—24	48 156	131 939	180 094	(7%)
25—34	121 555	317 654	439 209	(17%)
35—44	154 829	381 387	536 215	(20%)
45—54	157 555	357 649	515 205	(19%)
55—64	122 458	265 964	388 422	(15%)
65—74	76 635	214 632	291 268	(11%)
75—84	53 510	172 477	225 987	(8%)
85+	15 261	69 808	85 069	(3%)
Total <sup>2</sup>	749,958	1,911,510	2,661,468	(100%)
1.From Office for National Statistics (2000)				
2.Data may not sum, owing to rounding				

**Table 1.1 – Prevalence of depression in England in 2000. (The British Journal of Psychiatry (2003) 183: 514-519)**

There were estimated to be 2.6 million cases of depression in England in 2000 (Table 1.1) Twenty- two per cent of cases fell within the 65 and over age band - 17% of cases were female – 5% male. According to Pilgrim and Rogers (1999) approximately 2% of over- 65s are in residential care in the UK, an environment where depression is especially under-detected. These concerns were reflected in the Social Exclusion Unit (SEU, 2004) report which set out issues for adult mental

health sufferers including older people and confirmed the existence of undiagnosed depression, particularly in care homes. Pilgrim and Rogers's (1999) state there may be social explanations for the high rates of depression of older people in care homes. If an older person was considered a risk to their own safety or unable to care for themselves, a decision may be taken to admit them into a care home. This enforced separation from close friends and family may deprive the older person of the physical and emotional comforts they may have become used to at home. Additionally, Pilgrim and Rogers (1999) confirm that the loss of social or community life and the gradual erosion of close relationships that may have existed for many years, will be important factors that may contribute to the onset of depression and the resulting admission of the older person to a care home. In addition, major depression is the most serious cause of mood disorder affecting older people and accounts for over 60% of admissions of older people to psychiatric units (Spar and La Rue 1990) In a study by Cole and Bellevance (1997) out of 100 older people who were referred over a 30-month period to a psycho-geriatric unit, only 3% of the men and 20% of the women were found to be physically well and additionally, one third of those older people with dementia were also depressed and only one in five with a physical illness recovered from depression before death.

According to Clayton (1998) although social circumstances are significant risk factors, depression can be influenced through association with physical illness in older people because chronic pain may prevent an older person from performing activities which may have been part of their everyday life. Psychological factors

can also contribute to depression in older people. Although the loss of a loved one, close family member or friend is not limited to the experiences of older people, later life does bring with it an aggregating experience of loss. Furthermore, Clayton (1998) reported that not only do single and multiple bereavement increase the probability of diagnosable depression they also raise the probability of general illness. Pilgrim and Rogers (2003) conclude that the mental health of older people cannot be viewed as a direct result of one particular life-changing event but needs to be understood as a consequence of several determinants, entailing complex interactions between biological, psychological and social factors.

### **Professional Approach – Medicalisation and Medical Treatment of Depression in Older People.**

According to Pilgrim and Rogers (1994) professionals agree that depressive illness in older people should be treated as vigorously as it is with younger people because they are consumers within health and social care arenas and consequently, there needs to be a move away from `age` as a defining characteristic for allocation of resources (National Service Framework for Older People, 2001) Pilgrim and Rogers (1994) stated the dominant approach to treatment is rooted within the medical model suggesting depression should be treated in hospital, where the emphasis may be on the use of antidepressant medication. However, medication may remove feelings of depression but may not address the underlying problems behind the feelings, and consequently some professionals may have contributed to the `revolving door` analogy, whereby some older people are discharged from hospital only to be re-admitted at a later date. As

Pilgrim and Rogers (1994) conclude some older people who are re-admitted to hospital in a state of crisis may have been prematurely discharged and inadequately supported by community mental health services because the system appears to be designed to deal with crises, rather than avoid them, for example, through early intervention. A briefing presented by the Social Care Institute for Excellence (2006) states that accurate diagnosis and early intervention are important for all forms of mental illness in older people. The aim would be to keep older people out of hospital by providing an effective community care infrastructure through-

- The early recognition of physical and psychiatric conditions which can benefit the older person and avoid the use of inappropriate and dis-proportionate services.
- Early and accurate diagnosis of mental health problems which could enable older people and those caring for them to understand what is happening to them and to access appropriate treatment and help.
- Early and appropriate recognition and information that will help older people and their carers understand the present and prepare for the future.

These aims are underpinned and reflected in the *National Service Framework for Older People* (2001)( Standard 7) which emphasises that an integrated mental health service for older people should encompass the promotion of good mental health through early intervention and management of mental health problems.

#### Response to Prescribed Medication - Problems of Polypharmacy.

Anderson (2001) suggests that the poor medical response to depressed older people arises from several factors. Therapeutic nihilism based on misinformed

preconceptions of age and psychiatric treatment may be common and some doctors may have inadequate diagnostic skills and poor understanding of the concept of depressive disorder. Too often depression is considered a natural reaction to the vicissitudes of later life and is explained away as an inevitable and normal response. Ignorance of the associations of normal ageing makes therapeutic apathy more likely with older than younger depressed people. A study by Donoghue and Tylee (1996) of antidepressant prescribing in primary care found that older people were less likely to receive newer antidepressants than younger people. Older people quite often take longer to respond to antidepressants and the most common form of failed response is non-compliance with medication.

According to Hajjar et al (2007) older people have different more complex medical conditions and they metabolise drugs differently to younger people and for this reason there is a need for greater understanding of the responsiveness to and tolerance for medical treatments among older people. Polypharmacy, generally defined as the use of multiple types of medication at the same time, is more common among older people because they tend to have more medical conditions requiring medication. However some specific characteristics of ageing and geriatric medicine can make the prescription of appropriate medication for older people a more challenging and complex process. Hajjar et al (2007) conclude that there is evidence of inappropriate prescribing, over and under prescribing and a failure to review the continuing need for the medication prescribed. Inappropriate prescribing occurs when medicines are prescribed that pose more risk than benefit, particularly



where safer alternatives exist. It may also involve the use of an inappropriate dose for an inappropriate duration which may interact with other forms of medication being taken by the older person. Ryan and O'Mahony et al (2009) state that many older people are taking a wide range of drugs, sometimes unnecessarily, that their need for those drugs is not regularly reviewed, and that the interactions between drugs can cause further health problems, diminished quality of life, and unnecessary drug expense. Furthermore, according to Ryan and O'Mahony *et al* (2009) multiple drug use decreases the ability of older people to carry out basic daily activities and increases the number of symptoms reported. For example, according to Alagiakrishnan and Wiens (2004) all antidepressants can contribute to delirium – an acute confusional state. However, care is required - the most common sign of dehydration in the elderly is confusion although nutritional deficiencies may also cause confusion. Without careful assessment, delirium can be confused with a number of psychiatric disorders because many of the signs and symptoms are conditions present in dementia, depression, and psychosis.

Although medication is the most common reversible cause of delirium, it can also be used to manage symptoms of delirium, including agitation and aggression. Inouye et al (1996) has observed that the number of medications added before a delirium episode is a risk factor while Martin et al (2000) found an independent association between the number of medications and delirium. However, there are other causes of confusion in older people. DSM-IV contains reference to five dissociative disorders – one of which is dissociative amnesia which is an inability to

remember significant personal information or particular periods of time, which cannot be explained by ordinary forgetfulness. Stress and sleep problems can also make a person more forgetful (and this may include being worried about having memory problems) Furthermore, being under severe stress over a long period of time can cause memory loss that may be permanent.

### Electro-Convulsive Therapy (ECT).

Although medication may not be popular with some older people, it is the use of Electro-Convulsive Therapy (ECT) that arguably promotes a particularly strong opposition from service user movements. According to Coppock and Dunn (2010) ECT often arouses strong ethical objections in part due to its symbolic association with acts of torture, control and electrocution. Critics suggest that there is little evidence that ECT is helpful and a good deal of evidence that it can be harmful with Breggin (2008) claiming it damages the brain because it produces the same acute confusional state that occurs after any trauma to the brain. ECT was often prescribed by professionals in cases of schizophrenia when anti-psychotic medication proved ineffective, but its principal modern use is for cases of depression when anti-depressant medication has had little or no effect. The National Institute for Health and Clinical Excellence (2003:9) described the procedure;

During ECT, an electrical current is passed briefly through the brain via electrodes applied to the scalp, to induce generalised seizure activity. The individual receiving treatment is placed under general anaesthetic and muscle relaxants are given to prevent body spasms.

(2003:9)

A Department of Health (2007b) survey showed that in a three month period, (Jan – Mar, 2007) 2,835 people received ECT in England. Approximately 70% were female; 47% of which were 65 or over. Similarly, 30% were male; 45% of which were again 65 or over. Although Pilgrim and Rogers (1994) are highly critical of the use of ECT, the Royal College of Psychiatrists (1996) confirm some psychiatrists argue for its continued use, describing it as both a legitimate treatment option and the most effective treatment for major depression in older people. They consider ECT to be highly beneficial and insist it can often be a life-saving treatment for severe mental illness across all age groups and often used with older people when unwanted side effects of medication make treatment slower or riskier. Although anti-depressant medication is the first-line treatment, ECT is often used when it proves ineffective. However, Pilgrim and Rogers (1994) consider ECT totally unacceptable because it is not a permanent cure and it is understood that patients who do respond are likely to relapse at a later date and conclude that those clinicians who are convinced of the efficacy of ECT dismiss users' concerns as being unfounded.

Several studies (Murphy 1982, Woods, 1996) highlight the prognosis of depression in older people and concluded a significant number were not restored to full emotional health with the standard treatments available including ECT and consequently, many faced subsequent relapse. Murphy's (1982) year-long study reported that 42% of older people remained depressed following treatment - just 20% sustained a complete recovery. The remainder showed a partial recovery -

only to relapse within a 12 month period. Woods (1996) states that because of the available standard treatments, pessimism has long been typical of the treatment of depression in later life and concludes that the reason for this sense of therapeutic nihilism is complex, suggesting some older people are simply written off.

### Psychological Approach to Treatment.

According to Pilgrim and Rogers (1994) the mental health service users' movement is united on the importance of putting forward the views of service users, including older people, and seeking practical solutions that enable choice, for example treatment options. The movement has been highly critical of the use of biological treatments and continues to demand greater access to psychological alternatives. The aim of psychological therapies is to identify and change the factors that contributed to the older person becoming depressed and according to Dryden (2002) are synonymous with 'talking treatments'. Therapy involves techniques based around actions, exercises and words and can be delivered on an individual basis, or in groups, particularly families suggesting relationships can be a factor against depression. Dryden (2002) states cognitive behavioural therapy can be as effective as medication for treating mild to moderate depression and importantly, may be less likely to be followed by a relapse of depression compared to those people who take medication alone. There is increasing evidence that psychological therapies can benefit older depressed people, with Knight (1996) reporting that some older people respond better than some younger patients do to treatment, but to maximise the value of treatment, they need to present themselves

at an early stage of their depressive episode, which may require a family or social intervention. Knight (1996) confirmed some older people often present themselves at such a late stage that psychological intervention may be of little value.

#### Interventionist Approach for Reducing Depression in Older People.

Lyne *et al* (2006) conducted a research study exploring `intervention` as a mechanism for reducing depression among older people in care homes which comprised of twelve hours of training for care home staff, followed by two to three months working individually with depressed older people. Findings indicate that those depressed older people who received the intervention showed pronounced improvements and staff were very positive about the approach with Lyne *et al* (2006) confirming the results demonstrate scientifically how a holistic and person-centred approach can produce valuable outcomes. Consequently, Lyne *et al* (2006) states the interventionist approach offers a route towards major goals within the *National Service Framework for Older People* (2001) which suggests effective intervention in older people with depression may improve their quality of life and promote independence. Lyne *et al* (2006) concludes it may be possible to prevent the onset of mental distress by adopting a preventative approach rather than waiting for crisis after crisis to erupt and so avoid the possible need for compulsory admission to hospital.

## **Life Course Approach to Understanding Mental Health Problems in Later Life.**

The lifecourse approach is an alternative strategy which may help our understanding of mental health problems in later life by emphasising the importance of seeing later life as one phase of an entire course of life from birth to death shaped by earlier life stages and experiences. Meaning and identity are important to mental health in later life requiring a connection to past, present and the future in a person's life. The lifecourse has been traditionally viewed as the patterned progression of individual experience through time (Clausen, 1986) unlike the life span (the total number of years an individual lives)

In relation to this thesis, a lifecourse approach would suggest that in order to understand and work effectively with older people we need to see them in the context of their past lives, taking a life story or biographical approach to help see them in the context of their life history. Biographical approaches with older people stress the importance of individual life stories and include activities such as reminiscence, storytelling and life review work which is relevant to this study. Risk factors for poor mental health operate across the lifecourse and include a family history of psychiatric disorder, violence, childhood neglect/abuse, family breakdown, and unemployment. Bereavement, financial strain and long term caring are risk factors with particular resonance in later life (Milne et al 2001) A variety of data supports the significance of a lifecourse approach to ageing and also to mental health in later life. For example, a report conducted by Evans *et al* (2003) on mental health in older people found that they were three times more likely to

have mental health problems if they had ever experienced a financial crisis than if they had not - 29% compared with 9% - twice as likely to have mental health problems if they had ever experienced serious illness or injury - 14% compared with 7%, or if they had ever experienced separation or divorce - 18% compared with 9%, than if they had not. The strength of such an approach is the focus on the context of older people's life and the transitions and significant events occurring at different life stages that impact on health and well being from the formative years of infancy and childhood through adolescence, into adulthood and finally, older age.

According to Seymour and Gale (2004) a lifecourse approach to ageing is coherent with basic theoretical concepts of mental health promotion. Both models start from the position of viewing individuals as intricately bound up within a complex web of socioeconomic, environmental and broader structural relations. Both also allow for individual biological factors that operate across the lifecourse and often exert a cumulative effect in later life. Promotion of mental health and its evaluation at any time in the lifecourse is complex and challenging and has become a contested concept often associated with the absence of mental illness. This view is of fundamental importance to mental health in later life and should inform the design of interventions to promote mental health and also the evaluation of their impact. How older people think and feel not only about the here and now but also about the whole of their lives is of crucial importance to the enhancement and maintenance of their mental health. Seymour and Gale (2004) conclude there is a growing consensus that mental health is not only an individual construct but exists across

societies and imbues the structures within which we operate. Across the lifecourse mental health is influenced by many different factors - some are unique to an individual, such as family experiences while others operate across whole societies, such as the availability of employment or housing in a given area. Kendell and Zealley (1993) suggest that stressful past experiences throughout a person's lifecourse, and the appraisal of their current social circumstances play a part in the genesis of many illnesses – and a much greater role in the genesis of mental disorders. To remember what has happened in the past and to appraise current situations in the light of that memory are among the brain's most important functions. Kendell and Zealley (1993) conclude that it should not surprise us, therefore, that mental illnesses characteristically involve disorders of perception and cognition but most importantly memory, because it would be involved in both these activities – which may relate to some older people around the time of their assessment.

### **Can Older People Recover from Mental Illness? The Recovery Model.**

Recovery has a range of meanings and does not always refer to the process of complete recovery from a mental illness in the same way as people may recover from a physical illness. According to the Mental Health Foundation (2007) for many older people, the concept of recovery is more about staying in control of their lives despite experiencing a mental illness. The focus should be on supporting people rather than simply managing their symptoms to help them move beyond mere survival by encouraging them to move forward and carry out activities that give



their lives meaning. Fundamentally, the recovery model emphasises that although people may not have full control over their symptoms, they can have full control over their lives. The Mental Health Foundation (1997) claim social attitudes to mental illness often impose limits on people experiencing mental illness, but recovery is aimed at looking beyond these limits to help people achieve their own goals and aspirations. According to Deegan (1988) there is no agreed definition of, nor a single way to measure recovery. Nonetheless, the overarching message is that hope and restoration of a meaningful life are possible despite serious mental illness. Instead of focusing primarily on symptom relief, as the medical model dictates, Deegan (1988) suggests recovery should cast a much wider spotlight on the restoration of self-esteem, identity and on attaining a meaningful role within society. Anthony (1993) one of the most prominent proponents of recovery crystallised its definition,

... a person with mental illness can recover even though the illness is not 'cured' - recovery is a way of living a satisfying, hopeful and contributing life even with the limitations caused by mental illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness.

(Anthony, 1993)

Additionally, the Mental Health Foundation (1997) and the Social Exclusion Unit (SEU) (2004) confirm that on a positive note, there are links between recovery and social inclusion. The SEU (2004) state that these two principles not only guide mental health services, but are also fundamental requirements to support the inclusion of older people in the communities where they live by making it possible for them to take part in mainstream activities and opportunities. However, they

conclude that some services fail to empower their users to get back into the community, by assisting them to access social, educational and employment opportunities which can support the process of individual recovery. However, Wallcraft (2002) states psychiatric diagnoses can be frightening and may lead to despair in some older people and when coupled with the stigma and discrimination attached to mental illness, may become a barrier to recovery. Nonetheless, Wallcraft (2002) refers to several important factors aiding recovery, including good family and personal relationships, enjoyable activities, financial security and a suitable care plan being implemented. An emphasis is placed on the value of relationships, especially those that offer respectful listening, closeness, love and support, which are recognised as the most helpful during recovery. Mental illness is closely related to social and material deprivation, implying that efforts to promote mental health may need to consider social and economic needs rather than simply offering medical responses. As Wallcraft (2002) concludes, good quality relationships that offer practical and social support can often provide a meaning and purpose to life, but conversely poor relationships and lack of support can become a factor making recovery difficult.

### **Summary.**

This chapter has explored issues around mental health/illness and raises questions about how best to help older people who are suffering a form of mental distress. The precise extent of mental distress can often be difficult to understand, at least in part, because of our conceptualisation of mental illness and additionally, the

changes in definition and diagnosis which have shifted over time. From a professional perspective, the crux of the matter is recognising and diagnosing, with a degree of accuracy, that a mental illness either exists or does not exist. For example, where does sadness and distress following bereavement end and depression begin? However, from an older person's perspective, a purely symptom-based set of diagnostic criteria may fail to adequately take into account the extent to which their social circumstances, for example, their living arrangements, may have contributed to their mental distress – an important theme within this study. As Jones (2002) concludes, although an effort is made to address social factors, the whole process around diagnosis often flows from those professionals who operate from a predominantly medical model approach.

As the overall population ages, the situation of older people is becoming an increasingly important element in policy debates. Public attention and understanding has always been important in constructing both the way in which old age and mental health are understood and the nature of responses towards 'the mentally ill'. This review has revealed the tensions that exist around the societal response to mental illness in older people. Some older people within this study may be labelled as 'others' - often being defined according to their illness. Jones (2002) states that this 'label' is not self-imposed, but at times, 'placed' on them by society and is often accompanied by a set of assumptions and although discharge from hospital may remove the initial diagnostic 'label', the fact the older person has been in hospital, arguably the last bastion of the medical model in its purest form,

promotes them as having a psychiatric history and therefore not `normal` - so the stigma often remains. This has helped shape my understanding of the problems some older people with a mental illness face, which has not only impacted on my overall methodological approach, but also provided the platform to help answer my research questions and develop my research argument within the qualitative element of the study. It is not always a specific occurrence that causes older people to become depressed, but rather a culmination of minor stressful events, including social factors that may have contributed to the onset of depression - but the response is predominantly clinical. According to Jones (2002) the medical approach is a process aimed at containment rather than cure which may make it very difficult for an older person, who has been labelled mentally ill, to both operate and function within the boundaries of the `normal` non-depressive world. Additionally, it must be equally difficult to feel compelled to continue and persevere with prescribed medication, which may not do what it is supposed to do. Jones (2002) suggests anti-depressant medication may remove the symptoms of depression, but may do little to treat the older person's mental state and concludes that whatever the role of biology in underpinning what we understand as mental illness in old age, social factors clearly contribute to the origins of it, influence its progress and also impact on the prospects for recovery. Again, it is these tensions around the medically dominated approach to treatment for mental illness, which when combined with previous literature, for example, Pilgrim and Rogers (2003) have impacted on my research approach.

## ***Chapter 2.***

### **Mental Health Policy and Legislation Applicable to Older People**

#### **Introduction.**

The aim of this chapter is to explore how the discourses in the previous chapter are reflected in policy initiatives and mental health legislation in England and Wales.

Initially, there will be an overview of broader policy initiatives that have been implemented concerning the health and social care needs of older people, particularly those with mental illness for example, the Single Assessment Process for Older People. I will also discuss the use of the Mental Health Act (1983) with older people and the changes that were implemented within Mental Health Act (Amendment) (2007) This discussion will include considerations within the Mental Capacity Act (2005) an important element during the assessment process and the Human Rights Act (1998) which prompted and added to the perceived need for the reform of mental health legislation.

#### **United Kingdom Policy Initiatives Concerning the Mental Health and Social Care of Older People.**

The changing demographics of the United Kingdom (UK) have been reflected in considerable developments in health and social care policies for older people.

Harper and Leeson`s (2002; 2003) reviews of government policy aimed at promoting independent living for older people, confirm that a shift had occurred within the previous twenty years in both mental health and social care policy agendas with support for the role of the family a key conservative government objective. According to Harper and Leeson (2002) one of the governments's stated

concerns were to increase and promote independence. The Department of Health (DoH)(1989) emphasised the need for older people, including those with a mental illness, to *remain* at home for as long as possible and underpins the *NHS and Community Care Act* (1990) which aims to encourage community care provision that might *enable* older people to remain at home. Pilgrim (2005) stated the implementation of the *NHS and Community Care Act* (1990) fundamentally altered the balance between formal and informal care, disproportionately placing the burden of care on friends, neighbours and particularly the family.

Year	Major Mental Health Policy and Legislation Implemented since 1983.
1983	Mental Health Act (1983)
1990	NHS and Community Care Act (1990)
1991	Care Programme Approach (1991)
1998	Human Rights Act (1998)
2001	The Single Assessment Process for Older People (2001)
2001	National Service Framework for Older People (2001)
2005	Mental Capacity Act (2005)
2007	Mental Health Act (2007)

**Figure 2.1 – Timetable and Progression of Mental Health Policy and Legislation since 1983.**

Figure 2.1 above indicates how policy and legislation has developed and ultimately led to the introduction of the Mental Health (Amendment) Act (2007) The *Care Programme Approach* (CPA) (1991) was referred to as the cornerstone of the government's initiatives for mental health policy and became the basis for the care

of all people with mental health needs in the community. The DoH stated the CPA (1991) would be an important vehicle for change and also the framework to be used during the assessment of people with mental distress and at the time of discharge, with the added requirement for older people and caregivers to be fully included in the creation of a care plan, which would reflect Kitwood's (1993) inclusion principles within the person centred approach. However, according to Tew (2005c) the concept of 'care' underpins an approach to practice which is forever 'doing to' or 'doing for' inferiorised others and so does not sit easily with any philosophy of partnership in which 'doing together' might be viewed as more person centred. Tew (2005c) suggests there appears nothing implicit that suggests recovery is possible, but rather an assumption of ongoing disability and an inherent inability of people to fully take charge of their lives again and so become independent and concludes that this ideology is enshrined within the CPA (1991) because there is no provision for an exit strategy - people are assumed to be "risky and needy forever" (p:224) Rogers and Pilgrim (2003) supported this analysis emphasising their concern with the wider social context of some people with a mental illness arguing that the CPA (1991) has the effect of separating a person's treatment from their social context leaving them socially isolated - an area to be explored within this study.

McDermott (1998) examined the CPA (1991) from a 'patient perspective' and states there was evidence suggesting patients were unfamiliar with their treatment programmes and many lacked knowledge regarding their care. McDermott (1998)

commented that the pre-determined questions that required little more than yes or no answers and assessments that are often conducted in the absence of the individual person with mental illness, does little, if anything to positively contribute to the empowerment of the service user or caregiver, as per *National Service Framework for Older People* (2001) requirements. Phillips (1998) agrees stating that in practice, meetings can often be intimidating and some professionals may even disregard issues the older person has specifically requested to be part of the programme. As mentioned earlier, if older people are not involved and respected for their expertise in the design and delivery of their own care and treatment it may become difficult for professionals to identify their needs.

#### National Service Framework for Older People (2001)

The *National Service Framework for Mental Health* (1999a) focused on the mental health needs of adults up to the age of 65, possibly suggesting that at that time, concerns for older people with mental illness were not particularly high on the government's agenda. This was manifested by the exclusion of older people from the work and input of some functional teams such as Crisis Resolution Teams (CRTs) which were only provided for adults up to the age of 65, which could be viewed as discrimination on the grounds of ageism. Those older people 65 and over, were required to wait until publication of the *National Service Framework for Older People* (2001) which includes standards for the care and management of older people with mental illness. The *National Service Framework for Older People*



(2001) set out a ten-year programme based around the achievement of eight standards. Standards one, two, three and seven are relevant to this study.

Standard One. - Rooting out age discrimination.

Standard Two. - Person-centred care.

Standard Three. - Intermediate care.

Standard Seven. - Mental health in older people.

The *National Service Framework for Older People* (2001) identifies that within some health and social care departments, older people and their caregivers have experienced age-based discrimination. Standard one is intended to address this by involving older people in decisions about their care and treatment and provide mental health services, regardless of age, on the basis of clinical need alone which becomes important at the time of mental health assessment for older people within this study. This standard is supported and reiterated in the New Labour government's *Securing Better Mental Health for Older Adults* (2005a) policy, which states the social inclusion agenda is equally applicable to older people as it is to adults of working age. In other words, social inclusion policies are not aimed purely at those in gainful employment.

Standard two of the *National Service Framework for Older People* (2001) recognises the importance of involving older people in decisions related to their care and by doing so, ensure they are treated as individuals and receive appropriate care which meets their needs. These requirements are present in a report produced by the Department of Health (2004) which highlights several 'good

practice` examples of person centred care from health authorities around the United Kingdom. For example, the Age Well programme in Sandwell Health Action Zone (HAZ) was typical of work developed in partnership with older people within some HAZs, to ensure they had an equal voice in actively influencing policy and practice within partner organisations.

Standard three of the *National Service Framework for Older People* (2001) focuses on intermediate care to ensure older people have access to a new range of care services, either at home or in designated care settings, with the aim of promoting the older person's independence. The principal aim of standard seven is to provide older people with access to mental health services to ensure effective diagnosis, treatment and support for both the older person and their respective caregivers. There is an added emphasis on promoting prevention through early recognition and, when necessary, the appropriate management of the older person's mental distress. This may become particularly significant where the use of the MHA (1983) is being considered if true alternatives to detention are to become an option. While standard seven specifically addresses the provision of integrated mental health services, other aspects, including the goal of eliminating age discrimination and the delivery of person-centred care could also have a significant impact on the experience of older people within this study.

Despite the government's expressed intentions for the initiatives described above, Swann (2005) states coordinated approaches were not always experienced by service users, including older people, with many finding the whole system

confusing with no clarity about responsibility. To simplify the complexity of systems, the government introduced the Single Assessment Process (SAP) as part of the National Service Framework for Older People (2001) aiming to provide a more efficient assessment process and more effective care services for older people whereby agencies were required to coordinate their approach and share information to avoid duplication. The DoH (2002) issued guidance relating to the care of older people suffering mental distress advising that although the CPA (1991) focused on adults of working age, the principles are also relevant to older people. Finally, a document produced by Philp (2006) identified growing numbers of older people becoming involved in health promotion activities and an increasing number receiving help to remain at home rather than go into care and identified a new ambition for health and social care services that reflect the expressed wishes of older people and their caregivers – a more person centred approach. According to Philp (2006) there remained negative attitudes towards older people within the care system and a particular aim within the initiative was to ensure that older people were treated with respect in all settings, so acknowledging their `personhood`.

### **Implications for Practice; Working with Ambivalence.**

Despite the arguably well-intended aims and objectives of the *National Service Frameworks*, concerns remain. Philp and Appleby (DOH 2005) state that some older people with mental illness are missing out on the improved services that younger people are benefiting from. They suggest there is a notable lack of

understanding of how the wide range of mental health needs in older people may differ from those in younger people and consequently, some of the developments seen in older people's services are not fully meeting their, or, their caregiver's needs. Challis et al (2003) support the conclusions drawn by Philp and Appleby (DoH 2005) and conclude that this division in available services only serves to underpin concerns with `services based on age`. Additionally, a critical joint report, *Health System Neglects Elderly* (DOH 2006a) was published by three public sector watchdogs; the Audit Commission, the Healthcare Commission and the Commission for Social Care and Inspection, stating that older people were being neglected and poorly treated by the National Health Service. The report states that older people had become `second class citizens` and, if anything, the situation was being exacerbated by lack of consultation. One of the worst reported areas was mental health care, where older people found services deteriorating as they passed the age of sixty-five. Furthermore, a report published by Help the Aged (2006) stated health and social care services were failing older people - highlighting several criticisms. The main concern was that five years on from the introduction of the National Service Framework for Older People (2001) the very system designed to remedy past failures in the care given to older people could itself fail in key areas. The report states that patients` needs were not being assessed properly, because of limited consultation and co-ordination between older people, health care providers and social services.

The Help the Aged (2006) report concludes,

.... it is troubling to see that mental health services for older people remain the `Cinderella` service of an already neglected part of our health system. Mental health services for older people are in need of a complete overhaul.  
(Help the Aged, 2006:2)

Inpatient care forms an essential core component of mental health services, but has also received severe criticism outlined in a report by the Mental Health Act Commission (MHAC, 2006) Findings included psychiatric wards that were unable to provide patients with acceptable levels of security or care; intense pressure on beds and under-staffing; many patients fearful of mental health services and unpleasant ward environments which can undermine the therapeutic purpose of inpatient care. The commission notes that the problems were by no means endemic across all inpatient units, but were common enough to allow generalisation. In several units, drug abuse left some patients feeling unsafe and often at risk for their personal safety. Additionally, over-crowding led to bed pressures leaving inpatients with little space and staffing problems on wards denied them of little to do in terms of leisure activities of a more therapeutic design. The Commission confirmed officers found evidence of serious abuses of the rights of people with many wards being described as places of `squalor and degradation` - a description normally reserved for conditions during the asylum era.

This criticism from the MHAC coincided with several Department of Health guidelines on how services should be commissioned and delivered. "*Securing Better Mental Health for Older Adults*" (DoH 2005a) and "*Everybody's Business- Integrated Mental Health Services for Older Adults*" (DoH 2005b) both focus on the

mental health of older people. The MHAC report highlights the problems associated with delivering quality care and suggests that unless there is a real commitment to change and the allocation of `ring-fenced` capital and revenue to underpin service development, the state of acute care may undermine the delivery of the *National Service Framework for Older People* (2001).

### **The Mental Health Act (MHA) (1983) and MHA (Amendment) (2007)**

The Mental Health Act (MHA)(1983) (2007) provided (s) for the circumstances in which people from across all age groups, who are considered to have a mental disorder can be detained for further assessment which may ultimately lead to their detention in hospital and compulsorily treated. An application for detention may only be made where the criteria in either section 2 or section 3 of the Act are met.

A person can be detained for assessment under section 2 only if -

- the person is suffering from a mental disorder of a nature or degree which warrants their detention in hospital for assessment (or for assessment followed by treatment) for at least a limited period;
- the person ought to be so detained in the interests of their own health or safety or with a view to the protection of others.

A person can be detained for treatment under section 3 only if -

- the person is suffering from a mental disorder of a nature or degree which makes it appropriate for them to receive medical treatment in hospital;
- it is necessary for the health or safety of the person or for the protection of other persons that they should receive such treatment and it cannot be provided unless the patient is detained under this section; and
- appropriate medical treatment is available.

Additionally, the Mental Health Code of Practice (1983)(Revision 2008, par: 4.4) states that when judging whether compulsory admission is appropriate, professionals should consider whether there are alternative means of providing care and treatment for the person.

Policies Implemented in the Mental Health Act (2007 Amendment) Possibly Impacting on the Experience of Some Older People within this Study.

The Mental Health (Amendment) Act (2007) (parts of which became law on the 1<sup>st</sup> October 2007) is the first major legislation on mental health since 1983. The main provisions were implemented in October 2008, several of which may directly impact on the experience of older people within this study. According to MIND (2007) there are six main areas of the MHA (1983) which were affected when the MHA (2007 Amendment) came into force.

- There is a new broad definition of mental disorder and the removal of previous definitions within the MHA (1983).
- New safeguards have been introduced including a provision for advocacy and amendments to aid the displacement of the nearest relative.
- Supervised community treatment has been created through the introduction of a new Community Treatment Order for certain patients.
- The roles of approved social worker and responsible medical officer have been replaced and opened the door to a wider range of professionals.
- The `treatability test` has been replaced by an `appropriate treatment test`.
- Provision has been made for powers to reduce the time limits for the automatic referral of some patients to the Mental Health Review Tribunal.

The MHA (2007 Amendment) now has a single definition of mental disorder being `any disorder of mind or brain`. References to previous categories, for example, mental illness, mental impairment, severe mental impairment and psychopathic

disorder have now been abolished. Although the previous `broad` definition may not have resulted in any appropriate exclusion, it possibly provided the potential for serious over inclusion, particularly of those people who may not suffer from a mental disorder, but may, for example, have behavioural issues. Leaving aside the possible serious ethical issues, this could lead to the inappropriate detention of older people and, at times, be in conflict with the principle of least restrictive alternative.

The further development of statutory advocacy could be advantageous to some older people during the assessment process, most especially those lacking capacity to make informed decisions. Prior to the introduction of the MHA (2007 Amendment) advocates had no legal status, which denied them access to service users and prevented them from accompanying users to assessments or discharge interviews. However, their status, although currently recognised in law will need to be both accepted and recognised by mental health professionals if the fundamental principles, which underlie the aims of the MHA (2007 Amendment) are to be achieved. Similarly, changes have been made to sections of the MHA (1983) relating to the nearest relative and their `removal` or `displacement`. The terms nearest relative and next of kin are often confused and require some clarification. Within the MHA (1983) the nearest relative was a clearly defined person identified according to specific criteria and who also had a legally defined role within the MHA. The next of kin is normally someone who the person detained may prefer to regard as his or her nearest relative, but this may be someone who would not



come within the legal classification within the MHA. However, the nearest relative in the MHA (1983) (Amendment, 2007) now includes civil partners and as such, afforded the same rights as husband or wife. Additionally, the person detained can apply for `displacement` of their nearest relative on the grounds of them `not being able to act as such`.

The New Labour government bowed in certain areas following relentless pressure from social care charities and psychiatrists, but immediately sparked anxiety by pressing ahead with arguably, the most controversial element of the proposed bill. They introduced the use of Compulsory Treatment Orders (CTOs) - although restricted to those people who had been detained under a section three.

Compulsory treatment in the community continues to be an area of debate and the introduction of such powers remains contentious, although this action would break the automatic link between treatment and compulsory detention in hospital.

However, the introduction of CTOs may produce a positive response from some older people because of the decision not to admit them to hospital - which would also be in line with the recommendations of the MHAC.

#### Criteria for Discharge from Hospital under a Community Treatment Order.

According to Lawton-Smith and Burns (2009) under supervised community treatment, some patients compulsorily detained in hospital for treatment may, on discharge, be placed on a CTO (which some campaigners describe as `psychiatric Asbos`) requiring them to comply with certain conditions, including their medication

regime. Unlike existing supervised aftercare powers, supervised community treatment includes the sanction of conveying a non-compliant patient to hospital for compulsory treatment in effect as an out-patient, without the necessity of formal readmission. The shift made by the MHA (2007) (Amendment) to a comprehensive supervised community treatment confers the following principal powers,

- to require the patient to attend out-patient appointments
- to direct the kind or place of accommodation at which the patient will reside
- to supervise treatment
- to recall the patient swiftly to hospital, without the need for formal recertification to occur.

However, there has been much criticism of CTOs focused on the lack of evidence that firstly, they are needed and secondly, that they work. The Mental Health Alliance (2006) pointed out that the New Labour government had not produced any evidence from countries where CTOs were already in use on their effectiveness or on what does, or does not work. Mind (2007) stated that a review by the Cochrane Collaboration of Research on the use of CTOs in the United States of America, Australia, New Zealand, and Scotland confirmed there was no evidence that CTOs were effective in any of the main outcome indices: health service use, readmission to hospital within a year, social functioning, likelihood of being arrested, mental state, quality of home, homelessness or satisfaction with care.

A further concern is that an increase in the use of CTOs will be accompanied by an even greater reliance on medication. The high number of CTOs being issued is causing concern among mental health charities and professionals because according to Dunning (2009) the rates have far exceeded government expectations. Official figures show 2,134 CTOs were issued in England from November 2008, when they came into force, to March 2009. The government expected 350-450 to be issued in England **and** Wales in the first year. At the same time, the number of people detained in hospital under the Mental Health Act (2007 Amendment) increased by 100 to 47,700 in 2008-9. This is contrary to the government's stated intention to reduce the number of patients in hospital through the use of CTOs. Some older people may consider CTOs provide them with greater freedom and control over their lives, but undoubtedly, there will be concern about the potential implications for families, particularly the main caregiver.

### **The Mental Health Act (1983) in Action!**

#### **Comparisons of Admissions in England by Age and Gender (2008-2009)**

Table 2:1 below has been adapted from data gathered by the Health and Social Care Information Centre and shows the number of people by age and gender who were admitted to hospital in England, both formally and informally during 2008-2009. The rows and columns do not add up because they include inpatients for whom age and/or gender was missing or invalid (417 people in the year)

	Gender	Age				All ages
		Under 18	18-35	36-64	65+	
<b>Total informal inpatients</b>		783	18,313	29,659	21,166	<b>69,922</b>
Informal	Female	411	7,643	13,434	12,276	33,764
	Male	357	10,596	16,108	8,802	35,863
<b>Total formally detained inpatients</b>		329	10,956	15,128	6,236	<b>32,649</b>
Place of Safety	Female	7	148	197	16	368
	Male	13	236	271	19	539
Part II and other acts	Female	123	3,528	6,764	3,704	14,119
	Male	156	5,902	6,693	2,374	15,125
Court and Prison referrals	Female	6	135	226	27	394
	Male	19	969	924	70	1,982

**Table 2:1 – Numbers of hospital inpatients across all age groups in England during the year 2008-2009 by age and gender. (Source: Health and Social Care Information Centre, Mental Health Minimum Dataset (MHMDs) Annual Returns)**

Table 2.1 shows the legal status of people by age and gender who were detained during the year long period. People in the detained category are divided into detentions under Part 2 of the MHA (deals with compulsory admissions and guardianship) Place of Safety orders and Court and Prison referrals to give an insight into where people were admitted into hospital from. Table 2.1 indicates that more than three times more people 65 and over were admitted to hospital informally than formally. According to Pilgrim and Rogers (1999) most admissions to hospital are on an informal basis but regardless of what route people are admitted, there is an over-representation of women, including people 65 and over – which is also confirmed in the figures reported in table 2.1. Fifty-eight per cent of informal admissions were women compared to 42% men – similarly 59% of older people formally admitted were women compared to 37% men. Eastman and Peay (1999) note that most people who enter hospital do so via the administrative civil route and not from the criminal courts. Table 2.1 illustrates just over 19% of people

who were formally detained were 65 or over – and 97% within that age group were detained under Part 2 of the Mental Health Act (2007 Amendment) with less than one per cent of people 65 and over being admitted from criminal courts. Pilgrim and Rogers (1999) analysis takes the discussion further, in particular the over-representation of women stating there are competing explanations, two of which are discourses introduced in the previous chapter, that is, social causation - does society cause excessive mental illness and, social labelling - are women labelled more often than men? Brown and Harris (1978) identified different notions in the previous chapter which together point to the social origins of mental distress whereby a wide selection of factors interacting with each other may become pre-conditions possibly leading to mental illness. However, a different explanation for female over-representation may be explained by the influence of labelling theory, whereby patriarchal authority seeks to seek out and label women as 'mad' if they fail to conform to stereotypical gender roles, for example mothers and housewives.

### **The Bournemouth Case (1998)**

The MHA (1983) distinguishes between informal and detained patients. Informal patients are those who consent to admission and treatment, while detained patients are those who are compulsorily admitted under a section of the MHA (1983) The Bournemouth case (R v Bournemouth, 1998) involved a man HL with autism, who became distressed on the way to a day-centre and was eventually taken to hospital where he was assessed. HL lacked the capacity to either consent or object to medical treatment and was admitted informally and treated under the

common law doctrine of necessity. HL's caregivers wanted him discharged but their application was refused, so they commenced legal action to secure his discharge from hospital. Actions in the High Court, Court of Appeal, and the House of Lords followed, but it was the European Court of Human Rights (ECHR) who ultimately found that in the absence of the use of the MHA (1983), HL's rights to liberty and security had been violated. This ruling would have clear implications for the care of older people who lacked capacity to consent to treatment in hospital. The critical issues concerned the definition of deprivation as opposed to restriction of liberty and also, good practice in involving caregivers in the admission and treatment process. The ECHR was particularly concerned that professionals were exercising "complete and effective control" over HL's care and treatment, with total disregard to the wishes of his caregivers. Unlike detention under the MHA (1983) there were no procedural rules to prevent unnecessary restrictions of liberty and furthermore, no process by which a person might have their deprivation of liberty reviewed with the power to discharge if appropriate.

### **Mental Capacity Act (2005)**

According to the Mental Health Act Commission's (2002) guidance, compulsion should be avoided where possible when dealing with older people requiring mental health care. However, there may be times when a person who is suffering mental distress may lack the mental capacity to make an informed decision relating to their care and treatment. Prior to the Mental Capacity Act (MCA) (2005) being implemented, critics of mental health legislation, including the Sainsbury Centre for

Mental Health (2003), had argued it would have been useful to make capacity the pivotal concept within proposed draft legislation. However, according to Bartlett and McHale (2003) the Draft Mental Health Bill (2002) and the Draft Mental Capacity Bill (2005) developed in isolation within the legislative pipeline and there was a doubt if the two would work together. The Draft Mental Health Bill appears to have developed within a political atmosphere fuelled by media-inspired moral panic, emphasising social control and the need to protect people from those with mental illness, which produced a substantive legal framework. Additionally, there existed insufficient integration between both Bills, with neither providing the necessary safeguards for individuals who lacked capacity to consent to their admission to hospital and treatment. As Bartlett and McHale (2003) conclude, the Draft Mental Capacity Bill (2005) offered extraordinary informality around the decision making process, arguably stemming from an ethos of increasing reliance on family and caregiver support and the need for individual autonomy. It may have been unrealistic to expect reforms to be collapsed into one coherent bill, but a clearer acknowledgement of the differences between the two legislative frameworks may have resulted through pragmatic refinements.

The MCA (2005) may potentially have an impact on older people with mental illness, and so it is important to consider the concept of capacity within the context of the MHA (1983) As Laing (2003) states, the issue appears to be the way capacity is integrated within mental health legislation, because the MCA (2005) adopts a very different approach and philosophy to that which permeated the Draft

Mental Health Bill (2002) The former emphasised patient capacity, autonomy and welfare, whereas the latter focuses on risk management, control and public safety.

Laing (2003) comments the MCA (2005) provides a statutory framework to empower and protect vulnerable people who may not be able to make their own decisions, a situation that may arise within this study and so it should be clear who can make decisions in which situations and also, how the older person should go about meeting this aim. According to the MCA (2005) some older people may want to plan ahead for a possible time when they may lose the capacity to make their own decisions and, the Act allows them to do that. Although the Act was introduced in 2005, it was implemented in April 2007 and is underpinned by five key principles;

- *A presumption of capacity* - every adult has the right to make his or her own decisions, and must be assumed to have the capacity to do so unless it is proved otherwise.
- *The right for individuals to be supported to make their own decisions*- people must be given all appropriate help before anyone concludes that they cannot make their own decisions.
- *Individuals must retain the right to make what might be seen as 'eccentric or unwise' decisions.*
- *Best interests* - anything done for or on behalf of the people without capacity must be *in their best interests*
- *Least restrictive intervention* - anything done for or on behalf of the person without capacity should be the least restrictive of their basic rights and freedoms.

(MCA 2005)

According to the MCA (2005) older people can now appoint an attorney to act on their behalf if they should lose capacity at a future date, which may prove welcome for some, but consideration may need to be given to the amount and nature of



information advocates will require to make a decision that is in the 'best interests' of the older person. Chan (2002) comments that problems may arise when an older person has not made prior advocacy arrangements and consequently, acting in an older person's 'best interests' may not always accurately represent their wishes and at times, the approach may collapse into a paternalistic judgement which would produce an inadequate method of gaining consent. Chan (2002) concludes the powers of compulsion may lead to some professionals making decisions based less upon what is best for the older person, and more upon what the consequences would be if they did not compulsorily admit.

The MCA (2005) recognises some older people with a mental illness may be considered incapable of making informed decisions. Nevertheless, under the MCA (2005) older people are afforded the right to make their own decisions regarding treatment. Hughes and Baldwin (2006) maintain it is not the decision itself but the 'thought processes' that lie behind the decision which are relevant to the question of capacity which may become a problem for some advocates if they are to truly represent an older person's 'thought processes', and ask if we can ever achieve accurate simulations of an older person's 'best wishes'. Some older people may make decisions which seem irrational, but the law allows them to do so (MCA, 2005). As Hughes and Baldwin (2006) conclude, it is better to presume the person has capacity until it is clear he or she does not. Otherwise, the presumption that all people with a mental disorder are incompetent may quickly lead to deterioration in their standing and dignity.

According to Eastman and Pugh (1997) similar arguments to those above could be forwarded around the concept of `least restrictive alternative` commenting if the least restrictive alternative is to be a formative principle in providing ongoing care, then consideration needs to be given as to how it is to be implemented. For example, an older person living in the community and complying with care plans and medication rather than being hospitalised, may be defined as being treated under the `least restrictive alternative` guidelines. However, Eastman and Pugh (1997) argue that the whole concept comes down to definition and indeed, who defines `least restrictive` and conclude some older people may consider it less restrictive during an acute phase to be in hospital and not on medication, than in the community on medication, which seems to highlight the subjective dimension of `restrictive`. Atkinson et al (2002) agrees suggesting that conditions placed on some older people subject to a community care plan might be deemed highly restrictive to the point where they consider institutional living offers more day-to-day freedom. There has been a significant change to the Mental Capacity Act through the introduction of the MHA (2007) – the Deprivation of Liberty Safeguards (DoLS) which essentially addresses the Bournemouth case as discussed above. This amendment authorises the `deprivation of liberty` of a person, who lacks the capacity to consent to treatment or admission to hospital. A consideration of the person's `best interests` remains to help determine if the deprivation of liberty is essential to prevent harm or further deterioration in the person's mental disorder.

## **The Human Rights Act (1998)**

The Human Rights Act (HRA) (1998) came into effect in October 2000 and incorporates into United Kingdom law substantive individual rights while placing a requirement on all public authorities to act in a manner which is compatible with the European Convention on Human Rights (ECHR) The Bournemouth case provided an example of how articles within the HRA could be contravened, prior to the introduction of the MHA (2007) The enforced loss of liberty imposed on HL was in direct opposition to requirements within the HRA (Article 5) However, the Deprivation of Liberty Safeguards discussed above would now override these requirements, for example if the action was taken in the person's `best interests`. The HRA seeks to ensure that all laws, practices and procedures comply with the rights set out in the ECHR. The MHA (1983) has been challenged on several occasions for its compatibility with the HRA (1998) resulting in several successful cases including:

- the European Court of Human Rights suggested that 8 weeks was too long for a patient on a Section 3 to wait for his mental health review tribunal and breached Article 5. The MHRT should be heard as soon as reasonably practicable.
- Following a Mental Health Review Tribunal (MHRT) in which the patient under Section 3 was not discharged, an appeal was launched. The courts found that both Section 72 and 73 of the MHA breached Article 5 of the Human Rights Act. The wording of the sections has now been changed so that the MHRT must discharge the patient if it is not satisfied that the criteria for a section are met.

While the courts recognise the importance of respecting the medical professional judgments in implementing the MHA (1983) - the HRA (1998) has led to the court scrutinising the medical necessity of some treatments and the understanding of

consent. In the long term, this may have the potential to ensure that legislative procedures take into account human rights considerations proactively as a matter of course, rather than waiting for later challenges to existing laws. According to Age Concern (2002) there are several articles, which could have implications for older people who are subject to mental health legislation. The articles (in bold) described below are taken from the HRA (1998), with additional comments from Age Concern (2002)

- **Article 5- The right to liberty.**

**Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in cases and in accordance with a procedure prescribed by law.**

The Deprivation of Liberty Safeguards would now deal with this situation. However, this article will have been previously applicable when an older person had been detained without giving their consent. Everyone has the right to their freedom, including `persons of unsound mind`. The powers of detention under the former MHA (1983) and the present MHA (2007) would need to comply with Article 5.

- **Article 8- The right to respect for private and family life.**

**Everyone has the right to respect for his private and family life, his home and his correspondence.**

This article may be taken into consideration if an older person is removed from their family home, against their wishes - circumstances that may apply to some older people within the qualitative element of this study. Older people will also have rights concerning access to children, restrictions on correspondence and the identity of the nearest relative. I have presented these two articles because of their

relevance to this study and to help illustrate the change that has taken place since the introduction of the Deprivation of Liberty Safeguards. Prior to the introduction of the MHA (2007) (particularly the DoLS) there was a feeling that the HRA (1998) would result in a flood of legal cases concerning people with a mental disorder, particularly those detained under the MHA (1983) and so relates to Article 5, 'the right to liberty'. The broad scope of powers to detain and compulsorily treat people without sufficient safeguards in place within the MHA (1983) makes it incompatible with some provisions within the HRA (1998). Mental health law is both important and necessary – it is a source of focus for social changes, but alone may not be a sufficient step towards compliance with human rights standards.

### **Caregiver Policy and Legislation.**

Caregiving typically involves a significant expenditure of time, energy, and money over potentially long periods of time, often leading to psychological stress and physical exhaustion (Jones, 2002). The *National Service Framework for Mental Health* (1999a) enshrines the rights of caregivers to access services to help alleviate these pressures, while highlighting the importance of early assessment, not only of the older person, but also of caregiver needs. Since the *NHS and Community Care Act* (1990) the contribution that caregivers make in supporting older people in the community has been increasingly recognised and responded to. The Act introduced a broad requirement for local authorities to help vulnerable adults remain in the community, preventing or delaying admission to institutional care and required them to carry out assessments of people who appear to be in

need of community care services and to arrange packages of care. Most social services departments operate a set of eligibility criteria which define who is eligible for an assessment of need as well as support from services. The assessment process has largely been subsumed under the *Single Assessment Process* (2001)

The *Carers (Recognition and Services) Act* came into force in April 1996 and according to Coppock and Dunn (2010) for the first time it was stipulated that those providing `regular and substantial care` were entitled to request an assessment of their ability to care. The New Labour government introduced a *National Carers Strategy* in 1998 with the aim of improving information, support and care for all carers. The entitlement to an assessment and to be informed of that right was strengthened by the DoH (*Carers and Disabled Children Act, 2000*) and the DoH (*Carers Equal Opportunities Act, 2005*) which also required local authorities to take into account the carers` outside interests. However, Coppock and Dunn (2010) concluded that although these positive developments were welcomed by carers, their implementation has often fallen short of expectations. A revised *National Carers Strategy* was introduced in 2008 which outlined a set of commitments and a ten-year vision of what support for carers should be like by 2018 and stipulated.

- carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role
- carers will be able to have a life of their own alongside their caring role
- carers will be supported so that they are not forced into financial hardship by their caring role

(DoH 2008b)

The Audit Commission publication, *Forget Me Not: Mental Health Services for Older People* (2000) encapsulates the principles of `good practice` when delivering services to both older people and their caregivers. Additionally, the *National Service Framework for Older People* (2001) states that caregivers` needs should be considered as an integral part of the way in which services are provided for older people. Consequently, embracing caregivers as an important part of the system and also recognising that they may have care needs of their own can have positive consequences for older people, caregivers and mental health services.

Despite the intentions of the above policies and the existence of the HRA (1998) there is evidence of some potential human rights issues relating to caregivers that require addressing. A report commissioned by Carers UK, "*Whose rights are they anyway? Carers and the Human Rights Act*" (2006) suggests there are several articles where the carer`s rights may be violated. The report identified caregivers who delayed urgent medical treatment because of inadequate support, which would contravene Article 2 of the HRA (1998) `a right to life`. Additionally, some caregivers rely heavily on public services for funds, practical support and at times much needed respite. However, it is reported that many are pushed to the brink of physical and mental collapse because of a lack of support, which contravenes Article 3 of the HRA (1998) `a right to be free from inhuman or degrading treatment`. This may also contradict requirements within Article 8, `a right to respect for private and family life`. The Carers UK (2006) report suggests some local authorities may need to take account of the provisions within the HRA (1998)

requiring them to demonstrate they have fully considered a caregiver's needs before making any decisions pertaining to those needs.

### **Summary.**

Several important issues have been raised within this chapter which could become relevant within this study. The main consideration is whether the implemented changes within the MHA (2007) combined with existing proposals, for example, inclusion principles within the *National Service Framework for Older People* (2001) will lead to an improved experience for older people and their families. According to Tew (2005a) the challenge is how to 'unpack' the standards within the *National Service Framework for Older People* (2001) and connect them to those determinants that may benefit older people. Over the last twenty years there has been a significant shift in social policy discourse from a focus on tackling social 'exclusion' towards one of promoting 'inclusion'. Older people and caregivers are a very diverse group and thought must be given to representing different experiences and in ensuring inclusive approaches which will maximise the chance of people with very significant levels of mental distress and social problems to play full participatory roles within society.

The creation of CTOs has been a key driver for mental health legislation. However, the Mental Health Alliance (2006) state compulsory treatment in the community is an extension of coercion from which it may be very difficult to escape from, unduly interfering in an older person's right to run their own lives. They argue if the older person is deemed to require compulsory powers, then by definition, they should be



in a safe hospital setting. The Alliance states there may be ethical concerns relating to an older person who is functioning well enough to be living in the community while possessing the capacity to decide about their treatment, but find themselves living within the constraints of mental health legislation. Diamond (2007) claims tensions still exist between the MHA (2007) and the MCA (2005) because they are designed to cover distinct situations. Both Acts have taken a considerable time to develop and be implemented but the future will show if they can work well side-by-side and what, if any, modifications may be required. Both are significant in safeguarding the rights of older people but close monitoring will be essential to ensure they are effective in meeting this aim. Finally, people who care do so because they want to help the people they care about, but often it means they end up juggling the support they give with other responsibilities - a difficult balancing act. For many caregivers, looking after their own health, combining caring with work, getting access to training or simply having time to take a break can be a major challenge. People who provide a lot of care may have lower incomes, poorer health, and are less likely to be in work than their counterparts. If caregivers are to have the same opportunities as everyone else in society, and to be able to have a life outside caring, we need to improve support and recognition for what they do.

### ***Chapter 3.***

#### **A Multi-Perspective Analysis of Mental Illness, Assessment, Compulsory Detention and Outcomes Following Discharge from Hospital.**

##### **Introduction.**

Coppock and Dunn (2010) confirm that the mental state examination is the first formal stage in the process of becoming a user of mental health services.

Assessment and diagnosis is accompanied by a multi-disciplinary investigation into, not solely the person's mental history, but also their social history drawn from discussions with both the person being assessed and caregivers. There are several possible outcomes following assessment under the MHA (1983) The first is informal admission to hospital which occurs when a person voluntarily enters hospital for further assessment and if required, treatment for their diagnosed mental illness. The second possibility occurs when a person is formally admitted, that is compulsorily detained for treatment following assessment. This chapter will provide a multi-perspective discussion relating to the nature of mental illness, assessment, compulsory detention and outcomes following discharge from hospital. In the current mental health policy climate, the centrality of the service user perspective is increasingly being viewed as an integral and essential element at the time of assessment. However, the mental health debate encompasses a broad spectrum of experiences that affect all those involved in the assessment process so it is important they are explored.

As mentioned earlier, the highest profile change within the MHA (Amendment) (2007) was the introduction of supervised community treatment, which extends powers of compulsion in the community through Community Treatment Orders (CTOs) Milne et al (2001) confirm that in recent years, there has been a growing recognition of the important role that caregivers play in enabling vulnerable adults, including older people, to remain in the community. Consequently, this chapter will provide a brief insight into the role and experience of the caregiver considering the possible increased responsibility following the introduction of CTOs.

In 2002 a report published by the Social Policy Research Unit at York University stated there may be up to 6 million people in Great Britain involved in caring for a relative or friend and specifically, 1.5 million caring for a person with some form of mental illness. A further field of investigation and indeed one in which there has been increased interest since the introduction of the *Carer's Act* (1995) has been the perceived burden imposed on some caregivers who undertake the caregiver role. It is against this background of the growing importance of the caregiving role within both academic and political discourse, together with the concerns about the nature and site of caregiving that this particular discussion is placed.

### **Multi – Perspective View of Mental Illness.**

#### **Professional View – Mental v Physical Disorder.**

Pilgrim (2005) stated that illness can, in its most simplistic form, be defined as a state of poor health and includes both physical and mental illness. Professionals classify mental illness as either having an organic aetiology or alternatively, base

their judgements on the person's functional ability. Pilgrim (2005) continued stating organic mental illnesses, for example dementia, are defined by observable or measurable bodily abnormalities (signs) in addition to symptoms whereas functional mental illnesses, for example depression, are defined by abnormalities of speech and action (symptoms). From a professional perspective therefore, mental health is the ability to function within society which, according to Pilgrim (2005) is a social criterion - if a person can function they are mentally healthy, and if they cannot, they are mentally ill.

According to Bowers (1998) the debate over the true nature of mental illness can become polarised between those professionals arguing for a social and those arguing for a physiological aetiology with psychiatry finding itself at the centre of the debate - its status called into question by those who claim that to treat mental illness as a physiological ailment is to mask the social origin of the illness. Mental illness is seen by some professionals as a particular way of conceiving mental disorder but the inference of illness may medicalise a person's distress and so the implication often persists that mental disorders are disorders of the mind and fundamentally different from disorders of the body. As Bowers (1998) claims, mental disorder is a very inexact diagnosis, offering very little protection but it does meet part of the required assessment criteria, which can lead to compulsory detention. Psychiatry has historically been described as mental illness even though this term has embraced a far broader range of conditions including `mental disorder`, `psychiatric disorder` and `behavioural problems`. However, Bower

(1998) concluded their origins and meaning are the same, that is, there is something wrong with the person - they are viewed as mentally ill.

Matthew's (1999) questioned the term `mental disorder` asking what leads professionals to call a condition `disordered` and what justifies the distinction between mental and physical disorders. Some disorders are seen as mental, in that they consist of a failure to perform, or to perform effectively, certain characteristic human operations. These human actions, for example thinking, reasoning and remembering are generally classed as mental rather than physical, and can play some part in our ability to make decisions relating to our own welfare. However, according to Matthew's (1999) these deficiencies in mental performance could equally be classified as physical illnesses, because of possible disease or acquired brain injury and consequently, people suffering from physical illnesses may equally experience problems in thinking, reasoning and remembering. Hence, Matthews (1999) concluded that cases of this kind do not support any claims relating to absolute differences between physical and mental disorders which could have had implications for some older people within this study, particularly at the time of assessment when professionals were making decisions relating to the older person's mental distress and importantly, making a diagnosis.

#### Caregivers` View Of Mental Illness – What Works?

Providing care for an older person with a mental illness can be a complex, but often rewarding role. Caregivers are often faced with challenging and disruptive behaviour although this concept does require careful analysis because Kitwood

(1997) suggests that all behaviour is an attempt to communicate. If this observation was true, caregivers may need an awareness of the older person's behaviour and also the factors which have been shown to cause or exacerbate such behaviour to help prevent or reduce it when necessary. O'Callaghan *et al* (2010) state that aggression is common in older people with mental distress, with 15% - 43% of community referrals to old age psychiatry services and 44% - 65% of older people with Alzheimer's disease living in the community exhibiting such behaviour. However, Norman and Redfern (1997) conclude aggression impacts mainly on the wellbeing of the caregiver rather than the aggressive person.

The needs and interests of families and caregivers have received prominence in policy developments and legislation (DOH, 1999a, 2000) It was acknowledged that caregivers should be involved in service development, planning and delivery suggesting numerous ways to achieve caregiver involvement. According to Noble *et al* (2004) methods to increase caregiver involvement include –

- access to information
- involvement in decision making
- supportive staff
- good coordination among services

In terms of the evidence on caregiver involvement it has been reported that it is much less developed than service user involvement. According to (Keating *et al*, 2002, Arksey, 2002) some of the barriers to caregiver involvement include –

- lack of information
- perceptions by staff that family members play a part in causing mental illness and are interfering or over-protective
- patient confidentiality issues

However, despite the abundance of literature acknowledging caregiver needs, according to Collier (2007) their perspective is not always considered, so the true cost to them may not be fully understood. Collier (2007) suggests their may be caregiver frustration possibly because at times some professionals become distracted by anxiety around legal and ethical responsibilities which may become a source of anger and stress for the caregiver who ultimately needs information and guidance on how best to care for the older person. Collier (2007) concludes that some caregivers may be in a better position than some professionals to recognise 'what works best' with the older person as reflected in the *National Carers Strategy* (2008b) and so good intentions and best-interest arguments from a professional perspective may not always be helpful to the caregiver.

A compromise may help reach a mutual understanding of each others constraints and duties which can lead to a better understanding of the problems caregivers face on a daily basis trying to adapt to their new role and the limitations it presents to their own lives. A common thread runs throughout this plurality of overlapping knowledge bases. The viewpoints of professionals, older people, and caregivers reflects the complexity and diversity of experience based on a range of factors such as age, personal biography and family and social circumstances - factors that will be addressed in the qualitative element of this study. A multi-perspective approach at the time of assessment may show a commitment to both hearing and taking seriously what older people and their caregivers have to say relating to their mental distress and as Tew (2005a p:16) concludes, implies a shift away from a

discourse of `symptoms` in which the content of people's experiences is only seen as important in as much as it may "locate a person within a system of diagnosis".

#### Older Person's View – The Need for Inclusion.

Present day understanding of mental illness is still dominated by medicalised frameworks for assessment and treatment of mental illness although Beresford (2005) confirms service user knowledge now offers an additional basis for interpretation, as within this study, and may have fundamental implications for understanding their needs. For example, some older people with mental health needs may wish to stay in their own homes and remain independent for as long as possible. The emphasis on service user involvement, which according to Beresford (2005) entered mental health policy and practice in the late 1980s, has challenged and rejected medicalised understandings of a person's experience as pathological and have implicitly challenged the medical model in favour of a more social approach to both the assessment of needs and treatment. At that vital time, one key quality may have distinguished service user knowledge from that of all others involved in the field of mental health care – it is based on direct experience. Such service user understandings have developed from those trying to make sense of their own experience by collecting and sharing it, and according to the Mental Health Alliance (2002) have also emerged from efforts to make better sense of their experience than they feel the professionals have done.



A fundamental requirement of the *Care Programme Approach* (CPA) (1991) was to make the person's perspective central to any plan of treatment or care, which was affirmed as a central component of the Review of the *Care Programme Approach* (Department of Health, 2006) The CPA (1991) has been identified as the primary mechanism for involving service users in their own care and it is also viewed as a system for managing and co-ordinating care (NICE, 2002) Although Peck, *et al* (2002) found that when service users were involved in drawing up their own care plans, it had a positive impact on outcomes, Webb, *et al* (2000) evaluated the implementation of CPA (1991) and found that many service users were not involved in the care planning procedure nor did they have a copy of their care plan.

### **Personal and Social Circumstances of Older People Preceding Referral for a Mental Health Assessment.**

Older people may enter later life with an enduring mental illness or may develop mental health problems in old age. However, according to Sheppard (2002) the possibility that mental health problems may derive from social injustice and oppression is not widely recognised nor is the fact that older people with long-term mental illness are likely to experience social exclusion and discrimination. They may experience a vicious circle of social isolation, poverty, inadequate housing and scarce social and support networks (Social Exclusion Unit)(SEU)( 2004) There is evidence of unmet needs amongst older people, especially those living in rural areas where isolation and loneliness may be significant factors leading to mental distress (Scharf and Bartlam, 2006) Given the correlation between poor housing and mental illness (Rogers and Pilgrim, 2003) it may be beneficial to older people if

a specific requirement for suitable accommodation was included when considering their social circumstances as proposed within the *Care Programme Approach* (1991) and the *National Service Framework for Older People* (2001) Additionally, the *White Paper* (HMSO, 1989) which preceded the *NHS and Community Care Act* (1990) refers to `suitable good quality housing` being central to social care packages.

Other personal and social circumstances, for example negative life events or living with an ill family member are further factors recognised by the SEU (2004) as causing mental distress and often lead to referral for mental health assessment. Older people may have recently experienced bereavement or other family crisis, possibly caring for a family member for a sustained period of time. The associated stress and burden associated with the caregiving role can produce a negative impact on the older person's own health and well-being (SEU 2004) Professionals, caregivers and older people will have diverse and often conflicting perspectives relating to mental health services and as such the following section will consider the perspectives of those involved in the process. Moreover, there is increasing recognition of the importance of using different types of knowledge from a wider range of professionals, service users and community perspectives to help develop a coherent understanding of mental health practice (Pawson, et al, 2003)

## **A Multi-Perspective View of the use of the MHA (1983, 2007)**

### **The Professional Approach to Assessment.**

According to Zarit and Zarit (2007) assessment is the most important clinical skill when working with older people. When conducting an assessment, professionals draw on their knowledge of the normal ageing process and of symptoms of common mental disorders in later life in a systematic way to help determine a diagnosis. An older person who has been referred for assessment may be experiencing any of a wide range of disorders and it is important not to prejudge the outcome and given the many possible disorders in later life, assessment should start with a broad focus and narrow down the choices as information is gathered. Although assessment is a multi-disciplinary process, it is important professionals do not reach a conclusion prematurely or be persuaded by the opinion of the older person or their caregivers as that could lead to overlooking some important evidence that suggests a different outcome. As Zarit and Zarit (2007) conclude, ultimately, it is the how information is evaluated, rather than the use of any particular test or procedure that leads to sound clinical decisions.

With the development of multidisciplinary community teams, consultant psychiatrists, approved social workers and psychiatric nurses have learnt to work alongside one another (Bowers, et al 2003) This fundamental requirement will be paramount when an older person is referred for a mental health assessment when these teams will need to interact with general practitioners and at times, police and ambulance services. According to Bowers *et al* (2003) difficulties listed by doctors

were mostly practical ones, especially getting everyone necessary to the correct place at the correct time. For police and ambulance services, this was particularly acute if the request was urgent, rather than planned. Additionally, several doctors stated judging how a person may deteriorate can be problematic, as some present very well during the assessment and so the process can become difficult. The role of psychiatrists is crucial during the assessment to help determine if a person should be compulsorily admitted to hospital. If this action was found necessary approved social workers confirmed the need to act quickly - driven mainly by the concern that the person being admitted may become aggressive. However, appraisal of how often aggression occurs varied within Bower's *et al* (2003) study. Several doctors experienced frightening situations while one ASW confirmed he had been threatened regularly while another stated that, from his experience, violence did not happen very often. Similarly, CPN'S did not mention aggressive behaviour, but did complain of verbal aggression and commented that the police are normally the focus of any physical aggression.

#### A Caregiver's Experience of Assessment - A 'Struggle for Meaning'.

Poor communication through lack of knowledge on the caregiver's part, for example, the use of the correct terminology, may prevent relevant questions being asked of professionals at the time of assessment. As Barker *et al* (1998) state, some mental health professionals use language during the assessment stage that supports the powerful discourses of the professional disciplines, which effectively marginalises the perspective of the caregiver. The *National Service Framework for*

*Older People* (2001) encouraged collaborative partnerships and helped create an alternative to the medical model but, according to Jones (2002) some mental health professionals have a long history of, at best, a benign neglect of the role of caregivers which can leave them feeling excluded from the assessment process. Furthermore, Jones (2002) noted caregivers have little contact with the professionals concerned with the older person's assessment and treatment which often results in feelings of confusion, depriving them of the coping mechanisms required at a time of crisis and possibly adding to their subjective burden. As Brooker (2007) states, unless we let those in power know that caregiving is a skilled area of work, the lives of those people being cared for could be devalued – which is not person centred concluding that devaluing the caregiving role effectively devalues the older person being cared for.

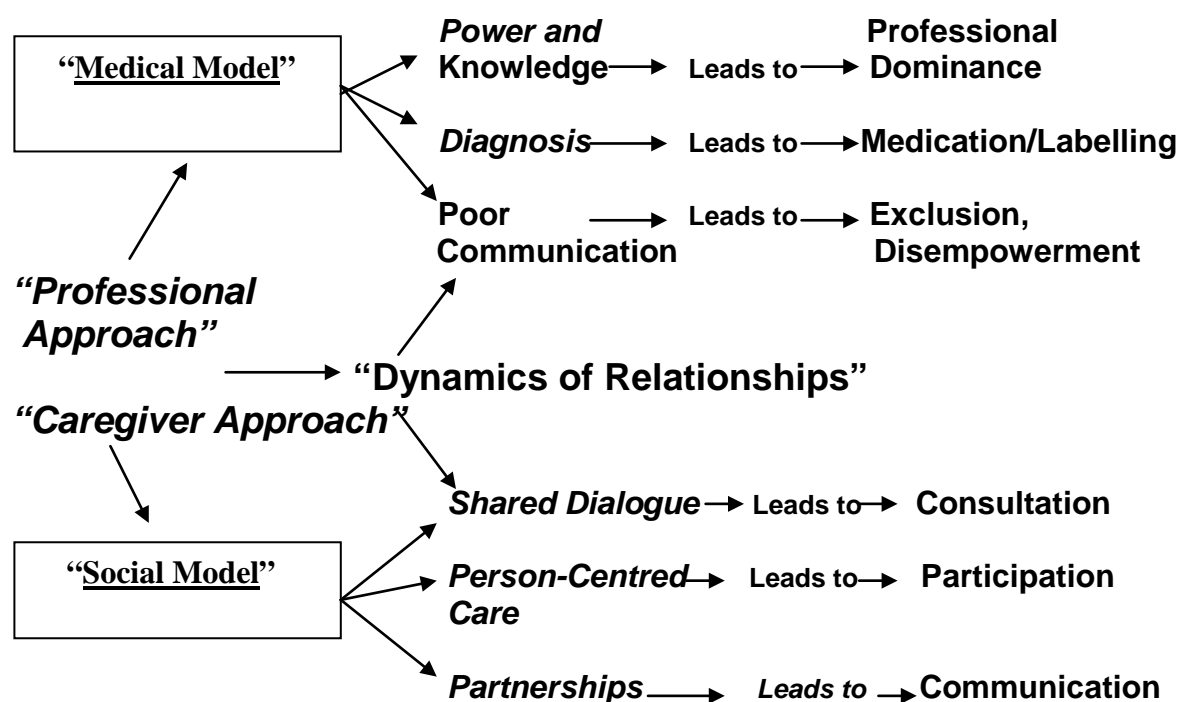


Figure 3.1 – Different Power Dynamics involved in relationships, Professional V Caregiver Approach. (Table adapted from the work of Jones, 2002)

An imbalance of power and knowledge may have a negative affect on professional-family relationships. Jones (2002) refers to the `expertise` and the associated `power differential` that operates between caregivers and professionals and highlights both the `paucity of information` and the resulting feelings of caregivers not being valued and involved in the caregiving process. Jones (2002) argues that although an intimate bond between the older person and professionals is seen as crucial towards successful treatment of the older person`s mental illness, there is little recognition of the benefits to be gained from recognising and acknowledging the supportive role of caregivers. For many caregivers, the central component is not care per se, but interpersonal dynamics (Figure 3.1) that can lead to good quality relationships. While care is an important part of the relationship, for some it may not be the overriding or defining characteristic. The main difference is the outcome and quality of relationship, which will be directly related to the approach taken. For example, professionals are often in a good position to facilitate the dialogue that good quality relationships are usually built on. However, if the dialogue becomes immersed within a medical model discourse, the relationship may become dominated by the professionals – leading to the exclusion of the caregiver which is reflected in Foucault`s (1977) analysis of power and knowledge – the role of professional discourse can have a significant impact on relationships between themselves, older people and their caregivers. On the other hand, because of a caregiver`s lack of power and psychiatric knowledge, they may adopt a more social approach – leading to a `shared discourse` that promotes communication, empowerment and inclusion.

Jones (2002) states there has been an increasing focus on gaining a better insight and understanding into the experience of caregiving by providing a `voice` for the caregivers, which is now reflected in the *`New Deal for Carers – Make your voice count`* (2007) Jones (2002:103) refers to the development of a “shared narrative” a shared discourse which functions to explain what has happened, why the older person behaves the way they do and why they need looking after. Caregivers may benefit from a shared understanding with the older person, but this may only happen through appropriate language and the sharing of information by professionals. However, this raises a possible dilemma for all involved concerning confidentiality and in particular, whose confidentiality needs to be respected - the older person's, or the caregiver's.

Hughes and Baldwin (2006) suggest that maintaining good relationships of any depth can be expected to be problematic and possibly, the more severe the older person's mental illness, the more fragile the relationship between professionals and caregivers. However, without concerted attention to the caregiver's emotional distress arising out of the older person's mental illness, it is possible that some kinship obligation may wither. The older person may then be left to depend on what social care services are able and willing to provide and, quite possibly, the result could be compulsory admission to hospital. Hughes and Baldwin (2006) conclude that good quality and lasting relationships could only be maintained through good communication between family members, professionals, and caregivers.

Jones (2002) refers to the caregiver's `struggle for meaning`, who express anger at professionals for seeming to withhold `meaning` through poor communication. The Audit Commission (2000) acknowledges the importance of caregiver involvement at the time of assessment and suggest a new approach to professional working may be required which clearly recognises the role of the caregiver, which might encourage them to become more confident about their abilities to care for an older person. Caregivers who are more knowledgeable and confident may place fewer demands on professionals and without their assistance, not only will the costs of care be substantially greater, the wellbeing of the older person could become compromised. The Audit Commission (2000) suggest that the `visibility` of caregivers in the policy process is important in terms of their political agency as a group, and conclude some professionals may need to recognise that mental health policy and practice is too important to be left to, or dominated by, one group. What may be required is a `team effort` with caregivers recognised as part of that team, especially during the assessment period and during discussions related to the older person's care package following discharge from hospital.

#### The Older Person's Experience of Assessment.

The *National Service Framework for Older People* (2001) includes clear reference to the importance of involving older people and their caregivers in the planning and implementation of health and social care developments. Some older people with mental health problems may want to exercise control over their lives and make choices which would help maintain their dignity and self respect while also



preserving their independence. Being involved in decision making about care planning is the starting point for developing a relationship based upon partnership between all those involved in the assessment process and is the first step in delivering a person centred service. The Single Assessment Process (2001) elevates the notion of person centred care from a desirable idea to a central value and mandatory practice during the time of assessment. However, a study conducted by the Personal Social Services Research Unit (2005) indicated that some professionals involved in the assessment of older people did not share an understanding of this value, and although upheld in theory, person centred care was often not adhered to in practice.

According to Foote *et al* (2002) problems around the time of assessment can develop when the objectives of the older person and professionals differ. Older people may be concerned with personal or family problems while the professionals may be focused on the formation and implementation of a treatment and care plan. As mentioned earlier, older people may feel excluded by the language used by professionals and so feel their concerns are not being valued and, as Foote *et al* (2002) states, for too long the knowledge and experience of older people as service users has been marginalised. Arguably, professionals should be assisting the older person to make informed choices related to their care in a mutually acceptable way which would reinforce the concept of person centred care. Foote *et al* (2002) concludes that the aim should be to build a partnership at the individual

level whereby the older person becomes a partner of the professional in the planning and implementation of their personal care plan.

### **The Process of Compulsory Detention.**

#### **The Changing Roles of Mental Health Professionals.**

According to the Mental Health Code of Practice (1983) professionals had defined responsibilities under the provisions of the MHA (1983) requiring them to apply professional judgements independently of each other, but within a `framework of co-operation and mutual support`. The MHA (2007)(Amendment) now provides for professionals from other disciplines to take on the role of the Responsible Medical Officers (RMO) who will now be referred to as `Clinical Supervisors`. The responsibility for this role will be opened up to, amongst others, social workers with the intention that the role be assigned by competency rather than professional status. Some doctors may feel their privileged position is now under threat, but mental health care has increasingly become multidisciplinary and furthermore, according to Coppock and Dunn (2010) a non-medical supervisor may present a more appropriate perspective on patients' social circumstances, particularly if compulsory admission to hospital is to be avoided and care is to be community based. However, the `broadening` of the role of professionals could be questioned on the basis of whether a professional, who is not medically qualified as a doctor, can provide the `medical expertise` to establish if a person is suffering from a mental disorder that justifies lawful compulsory detention.

The MHA (2007) (Amendment) has also `broadened` the group of professionals who can take on the former role of the ASW who are now replaced by Approved Mental Health Professional (AMHP) although their role within the process of application and assessment remains unchanged. The `independent` nature of the ASW was vital at the time of assessment and it is important that their social perspective is not lost. However, without social work training it may be difficult for some people from `other` professional backgrounds to fully appreciate and implement the unique and explicit value base, which is considered by some as inherent in good social work practice. For example, if a senior nurse or ward manager were to undertake the role of the AMHP, their role may be viewed as not independent of the medical profession and so find it difficult to take a non-medical view. McLean (2003) suggests that when an AMHP is employed by a different authority, they find it easier to go against a consultant's view than someone who is from the same authority and concludes multidisciplinary working will not be as effective.

#### The Family/Caregiver Experience of Compulsory Detention.

According to Rapaport and Manthorpe (2008) families are often involved in decisions about a relative's admission to mental health units for assessment and treatment, both on a voluntary and compulsory basis. During the early stages of a mental illness, it can be a frightening and confusing time not only for the older person but also for their family especially during the first admission of a relative into

hospital. Rapaport and Manthorpe (2008) continue stating family/caregivers may not know what to expect and what is involved in psychiatric care and treatment during an inpatient stay - this may also be particularly stressful for people whose relatives have been sectioned. The unknown aspect of what is involved and what is to come can be, for many people, extremely stressful. Knowing where to turn to for help and accurate information about the situation can help to alleviate some of this distress, but as discussed in chapter one communication is not always prominent during the assessment period.

Involving caregivers in mainstream debates may help the development of new frameworks for both understanding and responding to mental distress which may simultaneously `build` on the social model of disability. Some caregivers may benefit if they are included in the caregiving process and so have their `voice` heard. However, according to Jones (2002) services often remain dominated by professionals, which can have implications for caregivers because if they were recognised as an essential part of any proposed care plan, they may become included in shaping future services that affect both the older person they care for and importantly, their own lives. This approach may promote a more person centred approach and is reflected in the New Labour government's *`New Deal for Carers` - Make your voice count`* (2007) initiative, which emphasises the importance of gathering the views and experiences of caregivers. Instead of a `top-down` plan, the stated intention is to identify caregiver's priorities by engaging them in a nationwide debate via meetings and a dedicated website to provide

caregivers with a mechanism to express their wishes and opinions. This strategy is aimed at providing caregivers with an opportunity to gain the recognition they deserve while contributing to policies that ensure they have access to high quality and sensitive support when required.

#### The Older Persons` Experience of Compulsory Detention.

Broadly, there are two groups of older people to whom mental health legislation applies: those who develop dementia or depression in later life, and those with 'enduring mental health problems' (people with a life-long mental illness such as schizophrenia or manic depression) Most older people enter psychiatric hospital on an informal basis with detention being reserved for those who actively object to admission. However, possibly as a consequence of their unpredictable behaviour, which may include varying levels of aggression, many may require constant supervision and may even need to be restrained from leaving hospital for their own safety. According to Davies and Ryan (2007) in Neno et al (2008) working effectively with older people with mental illness requires an understanding of the experience of old age. The onset of any mental illness can also be seen as a time of transition, and this is particularly stressful, since there is usually a time of uncertainty prior to a diagnosis being reached. During this period, both family caregiver and care recipient can experience significant anxiety, as they will be unsure as to what they are facing (Farran et al, 2003) From the perspective of caregivers, changes in the behaviour of the older person with a mental illness and uncertainty about the future are often the most difficult aspects to cope with. During

their time in hospital, older people with severe mental health conditions may have difficulty in making and communicating decisions. According to Allan (2001) very few people are unable to be involved in making choices at all, but some may have partial or fluctuating mental capacity and may need help with communication. However, Allan (2001) confirms that pioneering work within the area of communication with older people with mental disorder has illustrated both the possibility and impact of supporting and training care staff in skilled communication practices, even with people whose verbal communication is limited – which would be vital prior to, and following admission to hospital.

### **Outcomes following Discharge from Hospital.**

Discharge from hospital can become a key concern for professionals, older people and quite often, the family if the care package is focused within the community. There can be several outcomes following the discharge of an older person from psychiatric hospital. Although their condition may have been stabilised, because of their continuing mental distress, their inability to care for themselves or their family's reluctance to undertake the caregiving role, a decision may be taken to admit them to a nursing home. Alternatively, the care and support they need may be available at home, and with a suitable individual care plan, a decision may be taken to allow their ongoing care to be undertaken at home, possibly under a CTO. The remainder of this chapter will discuss the options available when an older person is being considered for discharge from hospital.

### Professional Experience of the Discharge of Older People from Hospital Following Compulsory Detention.

Guidelines relating to the discharge of older people from hospital form part of the *National Service Framework for Older People* (2001) and are summarised here.

Hospital discharge is the term used when a person leaves hospital once they have sufficiently recovered. Before an older person is discharged from hospital, their needs must be professionally assessed so that any support or care services they may need can be arranged before they leave. Organisations that will be providing these services must be made aware of when the person is due to be discharged, and when they should be visited. If the older person's needs have changed considerably since they were admitted to hospital, they may require a multidisciplinary assessment which might involve the older person's consultant, nursing and ward staff, physiotherapists, occupational therapists and approved social workers. Conversely, if the patient's needs have not changed considerably, they may need a simpler assessment. The hospital discharge process includes,

- an assessment of the person's needs, living environment and support network
- a written care plan that records these needs
- confirmation that any required services are in place in time for the discharge
- a system for monitoring and, if necessary, adjusting the care plan to meet any change in needs.

The hospital discharge assessment should be carried out in line with the Single Assessment Process ensuring the hospital multidisciplinary team share information and work together to consider the older person's health and social care needs. The assessment might also consider whether the older person requires intermediate

care which refers to a range of support services designed to help them regain their independence so they can go home without returning to hospital unnecessarily. However, a decision may be made by the professionals involved in the assessment that the older person cannot return home but needs continuing care in either a nursing or care home.

### Discharge of the Older Person Back Home from Hospital – The Burden of Care?

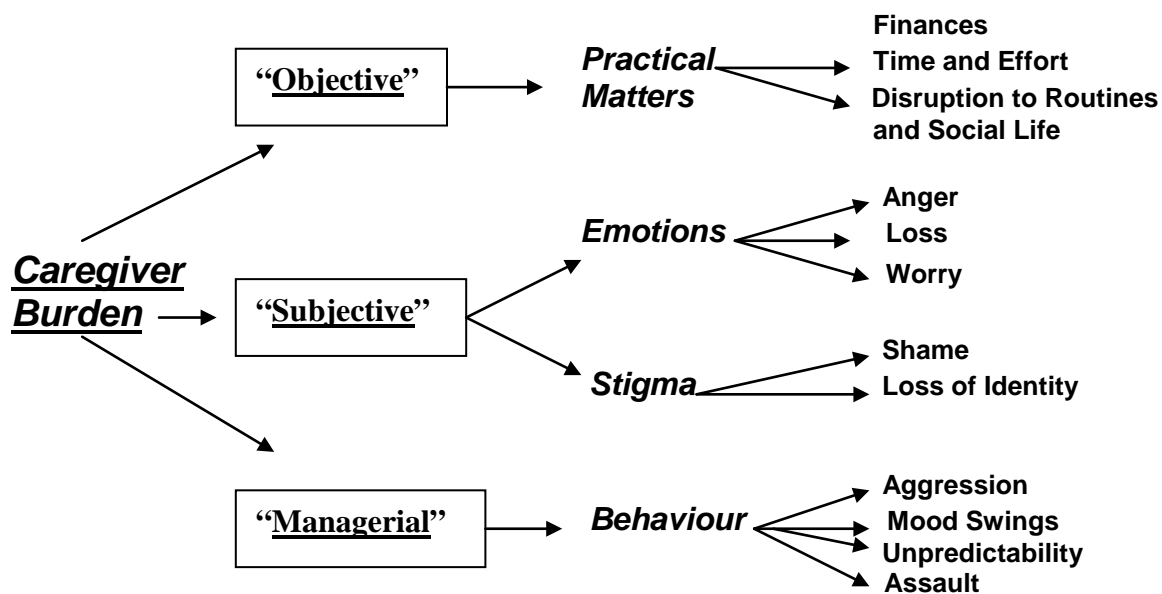
According to Lefley (1996) discharge from hospital can often `catapult` family members into being a caregiver, a role they might not want nor indeed have planned for – yet many undertake the role which they are not only unprepared for, but from which they have been historically excluded from in the past. As a result, family members are increasingly expected to perform complex tasks similar to those performed by health and social care professionals, often at a great cost to their own well-being. Following discharge from hospital, caring for an older person with a mental illness can present some family caregivers with specific problems. As a result of their `new` caregiving responsibilities, Lefley (1996) suggests some may give up other obligations, for example work to fulfil those caregiving commitments, which may lead to financial problems and social isolation. If the caregiver is in paid work, responsibilities may require a substantial change in lifestyle, something recognised within the *National Service Framework for Older People* (2001)

According to Arksey (2002) there is evidence that trying to combine caregiving and working can have adverse effects on caregivers themselves including, tiredness and lack of concentration; worry about caring responsibilities at work; and stress



brought on by trying to manage the often incompatible roles of employee and caregiver, each with its own pattern of conflicting demands and expectations. However, Arksey (2002) also suggests there is evidence that paid work may have a positive impact on some caregivers by providing an income and pension rights, helping to maintain social networks preventing social exclusion, offering a temporary relief from the caring role, and enhancing self-esteem while offering the opportunity to share concerns with colleagues. Caring for an older person with mental illness can become a seemingly endless burden, but according to Braithwaite (1990:6), burden “is very much a subjective phenomenon”. In other words, what becomes problematic for one caregiver may be quite inconsequential for another and so burden per se, cannot be regarded as a universal caring phenomenon. The caregiver experience may be further exacerbated if it becomes framed within a medical model of care which often undermines the position of the caregiver, by shifting the decision-making from them to the ‘experts’. According to Tew (2005a p:27) recovery from mental illness ‘cannot be ‘done to’ people, nor led by ‘experts’ who claim to know the destination and the route by which recovery is to be reached’.

It has been well documented that caring for an older person with a mental illness can produce associated social stigma (Lefley 1996) physical, emotional, social and financial problems (Wilkinson 2001) and involve tasks that may be both unpleasant and highly uncomfortable (Schulz and Martire 2004) which can negatively impact of the caregiver experience.



**Figure 3.2 – Burdens experienced by some caregivers of older people with a mental illness.**  
(Table informed from burden analysis by Lefley, 1996 and Wilkinson, 2001)

Although not specifically referring to older people, Lefley (1996) identifies three types of burden experienced by families caring for people with mental illness (Figure 3.2)

- Objective burdens in coping with the mental illness, for example, financial cost, time and effort required, disruption of daily routine and social life (Lefley, 1992; Lefley, 1996; Hatfield and Lefley, 1999)
- Subjective burdens in facing mental illness, for example, feelings of loss, shame, stigma, worry, anger and a feeling of helplessness (Lefley, 2000; 2001)
- Burdens in management of people with mental illness, for example, assault, mood swings, negative symptoms, and unpredictability (Lee *et al.* 2000; Bayer, 1996)

Objective burden involves practical matters, that is, anything that occurs as a disrupting factor in family life that is directly related to the person's condition. This can be anything from the worry of the financial effects of caregiving to the disruption of personal routines and of previous family roles. This may put further strain on family relationships and may be associated with family breakdown.

Furthermore, Lefley (1996) concludes that whilst it is often accepted as a worthwhile policy goal for older people to remain at home for as long as possible, the economic implications of shifting the burden of care to families has been largely ignored. Furthermore, caregivers may have been caring for an older person, possibly a parent, for many years and consequently, they may become socially isolated and detached from mainstream society, which can impact on their relationships because they may have forgotten how to speak to `normal` people. Older people often become increasingly dependent on the caregiver for help with activities of daily living which may include the need for personal care including bathing and dressing, which may become stressful for the caregiver. Singleton *et al* (2002) state that one third of caregivers have physical and mental health problems themselves - a point recognised in the *National Service Framework for Mental Health* (1999) and notes that some caregivers may need to access medical services themselves.

Subjective burden involves the feelings engendered by the objective burdens and refers to caregivers` emotional reaction to the caregiving role. According to Buijssen (2005) caregivers experience a sense of `loss` because the person they once knew has `gone` but adds that this emotion becomes compounded because the caregiver often fails to see the `loss` for what it really is - after all, the person is still alive. Some caregivers may also suffer a loss of freedom because the caregiving `role` has taken a complete hold on them both physically and mentally leaving little time for the consideration of their own needs.

Jones (2002) suggests there are several further factors directly linked to an older person's behaviour that may increase stress resulting in managerial burden.

Caregivers may experience changing and abusive behaviour, mood swings and unpredictability from the older person. The older person may become tired and confused and sometimes aggressive for no particular reason which may deprive the caregiver of the rewards of human interaction and reciprocity that some may expect from those they love. Consequently, the older person-caregiver relationship may become complicated, resulting in various outcomes depending on how the caregiver manages the situation.

#### The Experience of Family Caregivers - An Older Person's Admission into Care Following Discharge from Hospital.

Admission to a care home may be particularly significant to caregivers and may impact on their subjective burden, for example guilt, and the associated objective burden of financial management. If a decision is taken to discharge the older person into a care home, further expense may be incurred. Lefley (1998) states many caregivers are influenced by two important factors when choosing a suitable care home; location and atmosphere, which may raise the question - whose priorities are being met? Some caregivers may feel under pressure to choose a care home quickly, which can deny the older person the opportunity to visit a proposed care home prior to admission. Although some caregivers become active in attempting to locate a suitable care home, the experience could be described in a more passive sense, because at times, according to Lefley (1998) no one else may be willing to help. This may leave them feeling isolated and excluded and

although some caregivers may become involved in the discharge process, older people appear to be excluded, which could be viewed as a form of structural discrimination, whereby not just people with mental illness are disempowered, but older people in general.

Lefley (1998) states there is little understanding of how caregivers actually experience and cope with relocation of care. No longer at home, caregivers can feel out of place trying to care for a family member within such a setting, relegated largely to the position of `visitor`. Consequently, some caregivers may undergo a variety of experiences including loss of decision-making around social activities, medication and personal care. Lefley (1998) indicates that the burden of caregiving had been found to persist following an older person's admission to a care home. On admission, caregivers experience conflicting emotions searching for continuity and meaning in their new role. Assessment normally focuses entirely on the older person to the extent that the difficulties and challenges that caregivers experience are largely ignored, which could be seen as a further form of exclusion and not in line with requirements set out within the *National Service Framework for Older People* (2001) Fleming (1998) suggests that family caregivers can provide a lifeline of special care for the older person following placement, helping to sustain a `family connectedness` which can be beneficial to both caregiver and older person alike, while helping our understanding of the reasons caregivers continue their caregiving `careers`. However, Fleming (1998) concludes there are also indications

that the involvement of family caregivers is not always welcome and is rarely encouraged by care home staff.

#### The Impact of Community Treatment Orders on Families.

Community Treatment Orders have been discussed in chapter two but warrant a further brief discussion to consider what impact they may have on the lives of family caregivers. A community care bulletin by Mickel (2008) stated the change in the MHA (1983) could place a substantial burden of responsibility on caregivers adding that the Princess Royal Trust for Carers is concerned that, despite the code of practice, caregivers will not be as involved in the planning process as they should be. Supervised community treatment is intended to help 'revolving door' patients stay out of hospital by requiring them to accept treatment in the community. The policy's proponents claim this will allow recovery in a better environment - but potential problems have been identified at nearly every stage of their use. The bulletin contained several comments from prominent figures within the mental health arena. Policy development officer Drew Lindon suggests what is missing is a clear understanding by caregivers of when supervised community treatment is going to happen. Caregivers are not involved in the decision behind giving a CTO and do not understand what support they can access. Andrew Bailey, who chairs the Northamptonshire mental health carers' reference group, stated they have experiences of patients being discharged and turning up on caregivers' doorsteps without warning. Caregivers may be caught up trying to care for a loved one while acting as their warden because they lack any real guidance about what

to do if an older person breaks a condition of their CTO, for example not complying with their prescribed medication which could mean they are returned to hospital.

#### A Caregivers` Dilemma – An Older Person’s Non-Compliance with Medication.

Compliance with the medication regime is one of the criteria attached to CTO conditions of discharge which may become an added responsibility for the family.

The World Health Organization (2003) describes patient non-compliance with prescribed medication as a worldwide problem of striking magnitude noting that in the United Kingdom, 50% of older people do not take medicines as prescribed.

Causes of non-compliance with prescribed medicines vary. Wright et al (2006) argue that the main factors associated with poor compliance include,

- Adverse drug reactions
- Concerns about the value or appropriateness of taking medicines
- Complex regimens involving multiple doses and several medicines
- Practical difficulties or confusion associated with taking medicines.

Non-compliance may be defined as a medical term for `not doing what the doctor says`. Nonetheless, it is important to consider alternative ways of understanding this behaviour for example, the older person’s concerns about side-effects or forgetfulness. The Department of Health (DoH) (2001a) published a document as part of the *National Service Framework for Older People*. It set new national standards and service models for prescribing medication for older people, including concordance discussions, as part of the regular review of a patient's medications. This document advocated the development of home pharmacy services for older people, especially those with dementia or depression, in order to improve

compliance with their medication. It also requires practitioners to carry out periodic medication reviews, including assessments of whether the patient can access and take the medication easily, and whether they can read and understand all the written and verbal instructions. The DoH document highlighted that 45% of the medications prescribed in the UK are for older people aged 65 and over and furthermore, as many as 50% may not be compliant. The factors behind an older person's decision to take or not to take medicines are many and can be quite complex and may also change over time. Even if every measure has been taken to help an older person to take their medication, a range of other factors may still affect compliance. The Department of Health (2001a) document suggests compliance may be intentional or unintentional. Older people may *unintentionally* fail to take medication for the following reasons:

- They may not remember exactly how or when the drug is to be taken.
- Drug regimens may be complex and confusing, especially if they need to take more than one drug or their existing regimens are changed.
- If routines are interrupted.
- If problems are created by incipient dementia, impaired memory, or confused states.
- Older people may also reluctantly fail to comply because they cannot read the instructions that accompany their medication because of language and vision difficulties, and may have problems in opening containers, especially those with "child-resistant" tops.
- Older people living by themselves also often experience greater problems complying than those with someone there to remind them, or to help them to take their medication.



Corrigan et al (1990) adds further reasons why an older person may intentionally choose not to take prescribed medication may include the following:

- Inadequate information about why a drug is being given.
- Symptoms are perceived as only mild.
- Drugs or combinations of drugs have unpleasant side-effects.

However, according to Hatfield et al (1997) although non-compliance with medication is an important area of concern not all non-compliant people choose to reject their medication; some may simply forget to take it from time to time. Additionally, it may be difficult for some people to continue taking medication that may be causing considerable discomfort, which makes the whole concept of compliance problematic and furthermore, some people who have been prescribed medication may choose to come off it from time to time, to free themselves from an array of potentially unpleasant side effects. Hatfield et al (1997) suggest people should have the right to choose ill health, because the effects of prescribed medication may, in some cases, be even more distressing than the symptoms they are meant to be addressing and conclude non-compliance may indicate the failure of some professionals to offer an appropriate intervention that could allow a better outcome for the older person including an appropriate aftercare plan. However, some people may feel their lives have been so controlled by professionals that monitoring their intake of medication is the only power they have left, so adherence to medication may be an expression of independence by the older person, who by

simply complying with their prescribed medication is demonstrating they have the capacity to look after themselves.

#### The Older Person's Experience of Receiving Care.

Older people may interpret their experience of receiving care in different ways and may have a series of adjustments to contend with if they are to reach a degree of equilibrium in relation to their illness and so their care requirements. Baldock (1999) suggests a significant number of older people refuse help and services they are offered and more importantly, may need. Consequently, the way caregiving is 'received' by the older person following discharge from hospital may become implicit for care services. Both older men and women feel strongly about the need to maintain a sense of control over their own lives. Many older people may find accepting help incompatible with their images of themselves as independent adults and might prefer to view themselves not as dependent service users, but as 'whole persons' with lives of value and achievement. Baldock (1999) continued stating values of self-respect and dignity can become a concern when an older person harbours fears of dependency accompanied by greater fears of what the future might hold and concluded the older person's mental attitude rather than the physical reality may be more important and consequently, to accept help from a service outside of the family may be deemed an admission of weakness. Although the older person's material and physical needs may differ, the need for independence and dignity may always be present.

A particular finding emerging from Baldock's (1999) study suggests there are conflicts between the need for the older person being cared for to sustain their identity and self-worth and their acceptance of help and services and emphasised that self-esteem among older people is more likely to be sustained where there are increased contacts with caregivers. A further finding identifies the importance of the older person's biography and life review as discussed earlier and concludes that research had rarely focused on older people's accounts of the 'fit' between their needs and the help they may use. Purely from an older person's perspective, reflecting on one's own life history while maintaining one's own identity and self-esteem which has built up over a lifetime, may be more important than adjusting to appropriate or convenient solutions to the needs of later life. Old age can be viewed as a time of 'identity work' in which older people search for ways to sustain their self-images by linking their present circumstances to their previous lives.

The aim of care services for older people as reported within the *National Service Framework for Older People* (2001) is to help preserve independence, but it can be the fear of losing that independence that prevents some older people asking for help in the first place. Some older people may prefer to protect their independence because they may have negative images of services and low expectations of the benefits they deliver. However, the 'need for support' highlights the subjective nature of caregiving and consequently, it becomes important to consider individual needs as they will not be the same for everyone and would reflect a more person centred approach to care. According to Bowl (2001:118), the provision of care

services to “particularly older men may in itself undermine a notion of masculinity that is already potentially challenged by other changes wrought by the development of disability and dependence” and concludes that the loss of the `breadwinner` role and the related erosion of the idea of `mastery` in the domestic sphere will often impact on the older person’s `sense of self` and may invoke feelings of worthlessness.

### **On the Contrary - Some Caregivers Report a Positive Experience!**

Barnes (2006) offers an alternative perspective around the concept of caring for an older person with a mental illness, particularly relating to `burden`. Although Barnes (2006:11) agrees that caring is often demanding, she concludes “carers do not necessarily experience or describe caring as a burden”. Caring can also be a satisfaction, described by Nolan *et al* (1996) as the `neglected dimension` of caring. Barnes (2006) included three narrative chapters within her study, allowing family caregivers the opportunity to reflect and report their experiences - similar to the approach adopted within the qualitative element of this study. The narratives related specifically to caregivers of family members with a mental illness and highlighted several positive aspects of being a caregiver. Caregivers expressed signs of burden as described above, but they never described their caregiving role as a burden. However, the caregiver role may require analysis within a broader context, because they may view their role as more of a duty, that is, something expected of them rather than a burden imposed on them.

## **Summary.**

This chapter has explored the individual experience of those involved during the time of an older person's mental health assessment and following discharge from hospital, the impact caregiving can have on caregivers and on the older person they care for. The older person is at the very centre of their personal assessment and according to Jones (2002) they are experts on their own situation and may be able to inform professionals of what they feel will suit them best in relation to their care needs. However, the language of consumerism within the legislative framework has changed to one of partnership but it appears it is often a challenge to bring the `voice` of the older person and their caregiver into the system.

Partnership implies shared responsibility but there may be a need for a cultural change in some professional attitudes if this is to become a reality. Older people are a heterogeneous group and there are a wide variety of ways they can be involved in their care plan including direct participation at the time of assessment by providing an important and informed view of their problems to help find solutions. Older people have a key role to play during their assessment and care planning which may help develop quality relationships built on trust and mutual cooperation. Arguably, older people should be given what they want rather than what some professionals think they need.

The dominance of the medical model and its preoccupation with the diagnosing and treatment of symptoms associated with mental illness often fails to recognise the possible advantages of listening to and working with those who experience

mental distress. Critically, if professionals *shared* control and responsibility rather than simply *taking* control, this may help develop a more person centred approach to care. However I am not claiming the older person's / caregivers view is necessarily the correct way to view mental illness, but rather it may be how events are understood by them. What may be required is not necessarily a major shift in professional intent, but rather a realisation, an acceptance and an awareness of the potential benefits of sharing knowledge with the older person and their respective caregivers which may help inform practice in health and social care. However, the construction and discourses of caregiving largely focus on duty, burden and responsibility, rather than a sustained emphasis on the importance of person centred care. Social care within the family appears under-valued and yet it is often forwarded as an important element in addressing social changes in families and communities.

The burden associated with caregiving for a person with a mental illness has been well-documented (Lefley 1996, Wilkinson 2001, Jones, 2002). However, there is conflicting data on the factors that contribute to caregiver burden and some authors, including Barnes (2006) and Nolan (1996) suggest that for many people, caregiving can be a positive experience. Historically, studies in this area have tended to focus on the behaviour of the person with the mental illness and the burden and distress they may cause the caregiver. The caregiver's own social circumstances may play a major role in determining how burdensome they find their role and consequently, understanding the origins of caregiver burden may

have broad implications both in terms of the well-being of caregivers and the quality of care older people receive.

The material considered in this chapter illustrates how important informal caregivers can be to older people. New Labour Government reforms, for example, the introduction of the MHA (2007) (Amendment) may result in less older people being admitted to hospital, but not necessarily better recognition for caregivers which may lead to a reduced quality of care for those who need it. Similarly, the increasing transfer of older people into community care possibly under CTO conditions allows them to be cared for in more familiar surroundings. However, the added burden on some caregivers may mean the loss of paid work, not to mention the changes in personal relationships between those who care and those who are being cared for. A complete re-evaluation of the roles of caregivers may be required which could include a concerted effort to raise the status of `caregiver`. The gap between political rhetoric and reality does not appear to be closing, simply because the low status of `family caregiver` lacks both political and social priority, which may lead to disempowerment and exclusion.

It could be assumed that on entry to a care home, the `burden` of care transfers from the family caregiver to the staff within the institution. However, while the move to institutional care can sometimes bring relief from the physical and mental stresses associated with caregiving within the home, it may also bring with it a sense of `dislocation` from the process of caregiving. This may then produce new sets of largely un-addressed and unacknowledged anxieties and pressures for the

caregivers. Transitions into care homes are often complex with the boundaries between public and private `space` coming into question – so a further concern is with how these `spaces` are actively constructed in ways that act to include or exclude the family caregiver.



## ***Chapter 4.***

### **Research Methodology.**

#### **Introduction.**

This chapter will justify the approach to both data collection and data analysis. Initially, the search strategy for my literature review will be outlined before discussing the appropriateness of my philosophical underpinnings relating to my role as a researcher and my ontological and epistemological position which will be embedded in the literature. The methods adopted for data collection will follow before exploring the tensions and potential common ground between Interpretative Phenomenological Analysis and a Triangulated Case Study design. The process for gaining ethical and research governance approval and the requirement for gaining informed consent will also be discussed. I will discuss the sample population; the importance of pilot interviews and a brief analysis of those conducted for this study before describing the preferred approach to the analysis of the data gathered for the documentary and qualitative studies.

#### **Literature Review Search Strategy.**

This section provides the results of a literature search for past studies related to the use of the MHA (1983) and older people. I conducted an extensive search of relevant literature to identify and review past studies in the area and also, to help inform the study. I first sought to identify studies that met the inclusion criteria; older people who had been compulsorily detained under the MHA (1983) and the

inclusive age range. Initially, I `broke down` the research question to help guide the development of search terms - however, when I searched using a combination of terms, the number of `hits` received would have been unmanageable considering I was the only investigator for this study. As can be seen from table 4.1, when I searched `older people and mental health` in Scirus – I received 736,615 results which was not practical. Consequently, I included additional appropriate terms to provide more of a focus of the phenomenon being explored. In the review, I considered what has been written on older peoples` experience of compulsory detention to a psychiatric hospital from a range of sources (for example social work, psychology, sociology and psychiatry). I searched different types of literature on the `compulsory detention` phenomenon and admissions to psychiatric hospitals using database searches including Scirus, Pubmed, Wiley Interscience and Science Direct. I also found some articles using Google by means of an ad hoc approach, using the following keywords in different combinations: older people/person, the elderly, compulsory detention, formal admission, mental health/illness. Table 4.1 shows the results obtained. The literature review revealed the relatively little empirical social research focussed specifically on the experience of older people who had become subject to the use of the MHA (1983) No date restrictions were imposed.

	Keywords	`Wider` Search	No of Hits	Excluded	Included
Scirus	Older People, The Elderly Mental Health, Mental Illness, Compulsory Detention, Formal Admission, Mental Health Act.	736,615	384	366	18
PubMed	Older People, The Elderly Mental Health, Mental Illness, Compulsory Detention, Formal Admission, Mental Health Act.	1768	59	54	5
Wiley InterScience	Older People, The Elderly Mental Health, Mental Illness, Compulsory Detention, Formal Admission, Mental Health Act.	100822	96	85	11
Science Direct	Older People, The Elderly Mental Health, Mental Illness, Compulsory Detention, Formal Admission, Mental Health Act.	90,383	318	301	17

**Table 4.1 – Keywords used in Literature Review Search Strategy.**

According to Blaxter et al (2001) no electronic literature search can be 100% comprehensive, as the match between search terms and the content of articles will never be perfect. An electronic search may throw up a huge number of hits, but there are still likely to be other relevant articles not detected. Despite having access to electronic databases, it can be surprisingly useful to search relevant

journals manually to look through the contents pages and individual articles. Often hand searching journals can reveal ideas about focus, research questions, methods, techniques, or interpretations - a key idea can be discovered in this way. Consequently, I allocated time to search the most relevant journals that were not available electronically including Ageing and Society; Journal of Mental Health; British Journal of Psychiatry and Journal of Psychiatric and Mental Health Nursing reviewing them for anything of relevance.

### **Philosophical Underpinnings of the Study - Hermeneutic Phenomenology.**

One of the qualitative research methods available that aims to capture individual perspectives is that of hermeneutic phenomenology. The nineteenth and twentieth century, referred to in philosophical terms as the post-modern period, are a response to modernist thinking which proposes that truth or certainty can be found through empirical study. Leading the way is Heidegger (1962) who challenged the view of positivism, suggesting that we can only interpret the meaning of a phenomenon within the context of our background and that there is no definitive meaning in any experience. Hollway and Jefferson (2000) argue "If we wish to do justice to the complexity of our subjects an interpretative approach is unavoidable". Hence, phenomenological hermeneutics, primarily that of Heidegger (1962) underpins this study. For Heidegger, the task of hermeneutics was to understand the mystery of 'being'. Phenomenology is seen as the primary focus on the structure of 'being' (Heidegger 1962:29) and is concerned with describing and analysing human consciousness as it is perceived, independent of theories.

Phenomenology, therefore, could be understood as offering the possibility of understanding social and psychological phenomena from the perspectives of those involved. My approach therefore within the qualitative element of the study is couched within the phenomenological tradition, in particular hermeneutic phenomenology, relying on descriptions to help understand the lived experience the impact of compulsory detention has on older people. According to van Manen (1990) hermeneutic phenomenology is a process of exploring one's interests and understandings of a phenomenon by uncovering the essence of that phenomenon by gathering stories from those living it, by then interpreting those stories, which may then offer implications for practice. Essences are elements related to the true meaning of something that gives common understanding to the phenomenon under study. In characterising hermeneutic phenomenology, van Manen (1990) describes it as both 'descriptive and interpretative'. Effectively, this means the phenomenon speaks for itself but is also interpreted through the use of text in order to describe it. Each participant's experience sheds new light, not only on his or her understanding of the phenomenon, but also on the researchers understanding.

... to do hermeneutic phenomenology is to attempt to accomplish the impossible: to construct a full interpretive description of some aspect of the life world and yet to remain aware that life is always more complex than any explications of meaning can reveal

(van Manen, 1990:18)

According to Nenon and Embree (1996) the raw data of phenomenological research are based on personal experiences and offers a unique approach to understanding and interpreting individual experiences. The purpose of phenomenology is to allow the researcher to examine multiple identities and

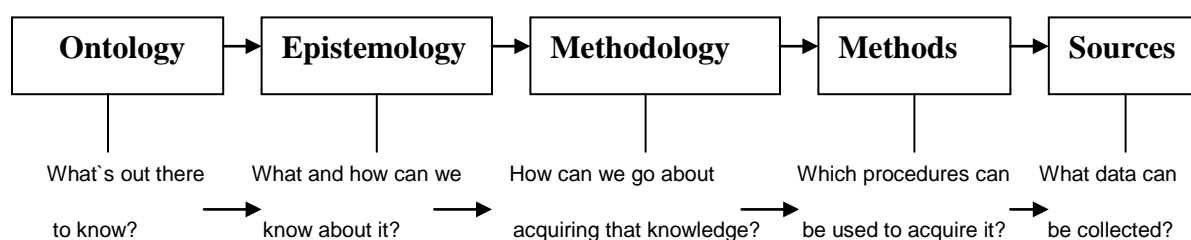
complex relations between those who are similar and those who are different. Phenomenological research provides the platform for participants, for example older people, to describe their individual experiences and so give meaning to events, for example their compulsory detention in hospital and equally, attributing meaning to their environment, for example `life on the hospital ward`. A phenomenological approach had direct implications for the methods to be used for gathering data. According to Gray (2004) phenomenology is one particular example of an interpretive approach and makes use almost exclusively of interviews, while emphasising the importance of adopting an inductive approach to the analysis and collection of data. Applied to research, phenomenology is the study of phenomena, their nature and meanings and Gray (2004) concludes that one of the recognised advantages of phenomenology is that, because of its emphasis on inductive data analysis, it is more likely to pick up factors that were not part of the original focus.

### **Justification for Methodology.**

My aim here is to justify my approach to data collection. The structure of this section will follow that presented in Figure 4.1. Initially I will discuss my ontological and epistemological position before describing my preferred methodology and finally, my preferred methods and sources for data collection including the design of the case study process.

### Ontological and Epistemological Position.

This section draws on the work of Mason (2002) and Grix (2001) who discuss the two philosophical concepts of ontology (what exists in the world) and epistemology (how knowledge is obtained about what exists in the world) emphasising the connection between qualitative research and the search for knowledge within the area of study.



**Figure 4.1 – Relationship between Ontology, Epistemology, Methodology, Methods and Sources. (Adapted from Grix 2001)**

According to Grix (2001) all of the stated research components are inextricably linked to one another in a logical manner. The chosen methodology is driven by certain ontological and epistemological assumptions and consists of research questions, the methods to be used in the study – and their justification – and, consequently, the data sources. These assumptions often underpin particular approaches to research. The information I required for this research existed `out there` (ontology) and I adopted a qualitative approach (methodology) in the form of one-to-one interviews (epistemology - method) to gather the data from all participants (sources) within my study. Mason (2002) provides a framework for the consideration of ontology and epistemology in research, stating that the overall aim is to demonstrate the ontological and epistemological “fit” of the design of the

research methodology. This refers to more than simply the research `tools` but is more concerned with the overarching structure of the research including the type of data being gathered, from where and how it is being interpreted. Mason (2002) suggests that in-depth interviewing would reflect these notions and proposes they are fitting if,

... your ontological position suggests that people`s knowledge, views, understandings, interpretations, experiences, and interactions are meaningful properties of social reality, which your research questions, are designed to explore, ... your epistemological position suggests that a legitimate or meaningful way to generate data on these ontological properties is to talk interactively with people, to ask them questions, to listen to them, and to gain access to their accounts.

(Mason, 2002:64)

It is important to examine the `fit` of the research methods with the overall ontology and epistemology of the study in question. The key concepts involved in the qualitative study were the interpretations of the experiences of older people to help generate explanations (epistemology) and the socially constructed nature of social reality (ontology). Mason (2002) concludes meaning is constructed not discovered, so within this study for example, older people constructed their own meaning in different ways - even in relation to the same phenomenon, that is their experience of compulsory detention. If ontology is about what we may know - epistemology is about how we come to know, what we know.

## **Methods and Sources for Data Collection and Analysis of Qualitative Study.**

### **Data Collection.**

Within the qualitative study there were several areas to be explored including how older people try to make sense of what people, for example, doctors are doing to



them and how they attempt to understand and interpret their actions. To address these questions one-to-one interviews were adopted. Bryman (2001) states one of the most significant aspects of much qualitative research is its participatory nature because those taking part are given value as participants rather than being purely research subjects. As referred to above, I have adopted an interpretivist approach for the qualitative element of this study in preference to a positivist or realist approach for several reasons. According to Bryman (2001) an interpretivist approach is aimed at understanding the subjective meaning of social action.

This study is focused on individual accounts and as such is subjective and value-laden which helps reflect the philosophical underpinnings of this research study, including the importance of multiple realities with the primary aim of understanding the expressed reality from those who have experienced it. According to Gibson et al (2004) the world is subjective, with an intended focus on meaning and interpretation to help understand what is happening through the induction of data, rather than confirming or refuting hypotheses. Alternatively, a positivist approach would emphasise the need for the study to be value free, hence objective, as would realism, which according to Bryman (2001) shares several features of positivism because it asserts that although there is a reality, it exists beyond what we are capable of describing. Hence, knowledge would require theory building, which would not produce real life accounts that could be justified and deemed reliable. On this basis, it could be argued that research involving people requires an approach that can only be seen as subjective. They are the subjects whose

experience within the social world we seek to explore and understand. Bryman (2001) concludes the interviewer is very much part of the process in that he or she is fully implicated in the construction of the interviewee's story. According to Bryman (2004) qualitative research is explicitly interpretative with the prime intention of describing, exploring and explaining the phenomena being studied which suggests it is the appropriate methodology to address the research questions. Adopting a qualitative approach, particularly one-to-one interviews, detailed sources of data can be accessed that might otherwise remain 'hidden' in quantitative research. Bryman (2004) states interviewing allows participants to feel they have a 'voice' that other people listen to because they are interested in their opinions and experiences, which they may not otherwise be able to raise within the context of other research methods.

At this point an acknowledgement needs to be made relating to the actual methodology which moved between a more open phenomenological approach and a tighter semi-structured interview approach, partly as a pragmatic response to the difficulty at times in eliciting sufficiently extensive and detailed narratives from some of the older people mainly because of ongoing cognitive problems. A phenomenological approach was used to map out people's experiences of compulsory detention mainly because it is a distinct method of inquiry providing a structured approach to investigate subjective experience, allowing the discovery of shared ideas and common experiences among participants. A traditional data collection method for phenomenological inquiry is the qualitative, in-depth interview

but because this method can be time-intensive, interviews are often semi-structured, hereby maximizing researcher efficiency while still allowing people's freedom of expression (Bryman, 2001) This method was judged to be appropriate to the phenomenological approach being used within this thesis because it provided a means by which individuals could tell their stories, in their own terms. The strengths of semi-structured interviews include the depth of information that can be gathered and the possibility that the participant can influence the topic, so unexpected issues may emerge. However, according to Bryman (2001) bias on the part of the interviewer needs to be avoided because the topic and areas of discussion is often pre-determined by the interviewer which may be important areas for the interviewer but possibly not so important for the participant.

### One-to-One Interviews.

Adopting one-to-one interviews as a research method allowed participants the opportunity to tell their story about specific experiences in their lives and produced their own account of their experience of compulsory detention which is consistent with the objectives of the qualitative element of this study. `Storytelling` is a vehicle often used in sociological research in which the individual tells others about a particular experience in their lives and is often described as a narrative feature in which the individual can tell their story, their way (Holloway and Freshwater, 2007) Mason (2002:63) suggests asking several important questions regarding why a particular research method may be preferred, in this case one-to-one interviews;

- Why might I want to use interviews?

- Why might I want to speak to or interact with people to generate data in order to answer my research questions?
- Why this style and approach rather than a more structured form of interviewing or questionnaire?

The researcher's answers to these questions are likely to be quite complex and will need to be closely related to the chosen research questions to help gain a "real life" insight into the circumstances surrounding the compulsory detention of older people. According to Mason (2002)

... knowledge is constructed through interaction involving the researcher and interviewee; meanings and understandings of the phenomena under discussion are created during this process.

(Mason, 2002:63)

Within this study, I explored both the experiences and meanings as expressed by all participants, inductively looking for patterns and themes, claiming my research was dependent on participants being studied within the complexities of `real` life. As stated above, my ontological position indicates that valid and reliable data is only accessible through talking to older people who have been compulsorily detained. Hence, it was not necessary to totally immerse myself in any particular setting, as an ethnographer might prefer. Rather my preferred method was able to support a study, which used interviews to explore people's individual experiences. This is a basic philosophical idea that underpins qualitative research. For example, within this study, the older person, more than any other source, possessed the knowledge and had vital information to share, which may enhance our understanding of their experience. Kagan (2007) suggests that more than anything else people want to be listened to and have their voices heard and concludes

social reality is embedded in their explanation, their interpretation, and their individual understanding of the socially constructed world they are part of. As Blaikie (2001) concludes, an interpretative approach seeks to understand people's perceptions from the `inside` rather than the `outside`.

The aim of one-to-one interviews is to elicit interviewee's reconstructed accounts of connections between events and also between events and contexts. As Bryman (2001) states, interviews are one of the main data collection methods in qualitative research, because they provide access to people's perceptions, meanings, definitions of situations and construction of reality. In short, they are one of the most powerful ways we have of understanding others. Consequently, one-to-one interviews were adopted as the principal qualitative method within this element of the study for gathering data, because of the flexibility it offered and the ability to adapt to suit a wide variety of research situations. As Gluck (1991) suggests, if we need to know and understand about the lives of different people in different situations, we need to interview them at length, in depth and in an unstructured way.

Within this study, the interaction between me as the researcher and the older person was crucial to ensure the authenticity of what was reported. The focus was how events appeared and how they are then interpreted through individual experience. According to Todres (2007) it is then up to the phenomenological researcher to provide a rich textured description of that lived experience. Hence, the challenge within this study was to help participants express their experience of

detention as directly as possible to help reveal fully their lived experience. However Todres (2007) explains the quality of the data was also dependent on the older person's use of language to present an account of their personal experience of compulsory detention from start to finish. The role of the researcher then lay in their ability to interpret and structure the gathered data into a form which clearly presents a sense of understanding to help improve the limited knowledge of the phenomenon being explored.

#### Data Analysis - Interpretive Phenomenological Analysis.

According to (Smith, 2004) Interpretative Phenomenological Analysis (IPA) is a relatively recent qualitative approach developed specifically within psychology but is now being used widely by researchers in health, human and social sciences. According to Chapman and Smith (2002) although it is possible to obtain data suitable for IPA analysis in a number of ways (e.g. personal accounts, diaries) the best way to collect data for an IPA study, and the way most IPA studies have been conducted, is with semi-structured interviews – which is consistent with its theoretical commitment. This allows the researcher and participant to engage in a dialogue whereby initial questions are modified in the light of participants' responses and the investigator is able to probe interesting and important areas which arise which enables the participant to provide a full, rich account. IPA researchers usually try and find a fairly homogenous sample. The basic logic is that if one is interviewing, for example 10 participants, it makes little sense to think in terms of random or representative sampling. IPA therefore uses purposive

sampling to attempt to find a more closely defined group for whom the research questions will be significant.

IPA is concerned with trying to understand lived experience and with how participants themselves make sense of their experiences and is therefore centrally concerned with the meanings which those experiences hold for the participants. IPA is phenomenological in that it wishes to explore an individual's personal perception or account of an event as opposed to attempting to produce an objective record of the event itself. Thus, one important theoretical touchstone for IPA is phenomenology, which originated with Husserl's attempts to construct a philosophical science of consciousness (Smith & Osborn, 2003) At the same time, while trying to get close to the participant's personal world, IPA considers that one cannot do this directly or completely. Access is dependant on the researcher's own conceptions which are required to make sense of that other personal world through a process of interpretative activity. A second important theoretical current for IPA is, therefore, hermeneutics - the theory of interpretation as discussed above (Smith, 2004) According to Smith & Osborn (2003) IPA is also a strongly idiographic approach concerned with detailed analysis of the case either as and end in itself or before moving to similarly detailed analyses of other cases. Within this study, it involved a detailed case-by-case analysis of individual transcripts with the primary aim of examining in detail the perceptions and understandings of the participants. A successful analysis is interpretative by nature and thus subjective

so the results are not given the status of facts and transparent, that is, grounded in examples taken from the data.

IPA is considered a particularly relevant method for this study as it aims to give a `voice` to and interpret the personal experience of participants and how they make sense of their experience. IPA is also interpretative in recognizing the role of the researcher in making sense of the experience of participants. Smith (2004:40) refers to double hermeneutics – “the participant is trying to make sense of their personal and social world; the researcher is trying to make sense of the participant trying to make sense of their personal and social world.” IPA provides flexible guidelines which can be adapted by researchers in accordance with their research aims (Smith & Osborn, 2003) Analysis for this study followed several stages: The first consisted of reading the written responses to interview questions and also, once completed, the transcripts of all participants and the audio recording several times to become immersed in the data. During this process, notes or comments which appeared significant or interesting were recorded. The second stage involved returning to the written interviews and transcriptions to transform the initial notes into emerging themes or concepts, taking care not to lose the connection between the participant’s own words and the researcher’s interpretations. In the final stage, a table was produced showing the structure of major themes and sub-themes (Fig. 7.1)



### **The Triangulated Case Study Design Process.**

Case studies were used within the qualitative element of this study to explore the research questions. Each individual case was made up from an interview with one participant from each group that is, one older person/caregiver/consultant-doctor/ASW, which produced fifteen cases for thematic analysis. According to Gray (2004) case studies explore subjects, for example, older people within this study and issues, for example, the use of compulsory detention where relationships may be ambiguous or uncertain. Additionally, rather than simply describe a particular situation or phenomenon, case studies can also attribute causal relationships, for example the older person's social circumstances. The case study approach is particularly useful when trying to uncover a relationship between a phenomenon and the context in which it is occurring. For example, within this study, I explored the social circumstances of older people prior to their assessment to consider if these factors may have contributed to their mental distress and ultimate admission to hospital. Gray (2004) concludes case studies can prove invaluable in adding to understanding, extending experience and increasing conviction about a phenomenon. According to Bryman (2004) a case study provides a systematic way of looking at events, collecting and analysing data, and finally reporting the results and concludes that often, what a case study exemplifies will only become clear after it has been completed and analysed. It may be that it is only at a very late stage of the case study process its significance becomes apparent.

There has been no previous research that has specifically explored the experience of older people who have become subject to compulsory detention. It was my

intention to interview 15 older people; 15 family members; 15 consultants/doctors and 15 ASWs. However, one older person (Edward) died during the course of the study and another older person (George) had no family member to interview. Hence I interviewed 14 older people; 14 caregivers; 15 consultants/doctors and 15 ASWs which provided an example of gathering data through triangulation. Denzin (1989) comments that data triangulation refers to data that has been collected using multiple sampling strategies which entails gathering data from more than one source of a social phenomena. Data for this study were collected about the same phenomenon from four separate perspectives (person triangulation) as described above so that findings could be cross-checked. Blaikie (2001) supports the notion of obtaining more than one account of an event, aiding triangulation and providing the fullest description.

### **The Tensions and Potential Common Ground between the Two Qualitative Methodologies.**

Although there are arguably tensions between the two qualitative methodologies discussed above there also exists potential commonalities between Interpretative Phenomenological Analysis (IPA) and a Triangulated case study design. A frequent criticism of case study methodology is that its dependence on a single case renders it incapable of providing a generalizing conclusion. Yin (1993) presented Giddens (1984) view that considered case methodology 'microscopic' because it lacked a sufficient number of cases. Yin (1993) forcefully argued that the relative size of the sample whether 2, 10, or 100 cases are used, does not transform a multiple case into a macroscopic study. The goal of the study should

establish the parameters, and then should be applied to all research. In this way, even a single case could be considered acceptable, provided it met the established objective. As Smith et al (1997) confirmed a single case study can generate rich and particular accounts with the aim of either `problematizing` existing concepts or helping develop ways of looking at new areas of study. Nonetheless, the exploration of one phenomenon, as within this study, from multi perspectives can help the IPA analyst develop a more detailed and multifaceted account of that particular phenomenon which is a form of triangulation.

According to Smith et al (2009) IPA utilizes small, purposively-selected samples and may often make very effective use of single case analyses although he confirms, a study usually involves more than one case. However, in a multiple-case study, each case should be analysed on its own terms to do justice to its own individuality by `bracketing` out ideas emerging from previous cases which is in keeping with IPA`s idiographic commitment. Some researchers may decide to identify emergent themes at case level and not search for patterns and connections until examining all the cases together. However, as (Smith, Flowers and Larkin, 2009) conclude, even where the analysis is primarily at group level, what makes the analysis IPA is that the group level themes are illustrated with particular examples taken from individual cases – each claim is supported with material from the participants.

Smith (2009) suggests there is no right answer to the question of the sample size. It partly depends on several factors: the degree of commitment to the case study level of analysis and reporting, the richness of the individual cases, and the constraints one is operating under. For example, IPA studies have been published with samples of one, four, nine, fifteen and more. There has been a trend for some IPA studies to be conducted with a very small number of participants. A distinctive feature of IPA is its commitment to a detailed interpretative account of the cases included and many researchers are recognizing that this can only realistically be done on a very small sample – thus in simple terms one is sacrificing breadth for depth. The danger for the newcomer and possibly a critique is that if the sample size is too large they become overwhelmed by the vast amount of data generated by a qualitative study and are not able to produce a sufficiently penetrating analysis.

### **The Ethics Requirement.**

Research involving human subjects requires ethical approval and quite simply, without approval, the study will not be allowed to commence. Because of the nature of this study and the voluntary participation of older people, a fundamental requirement was to obtain ethics approval from the Local Research Ethics Committee (LREC) who form part of the Birmingham and Solihull Mental Health Trust. The LREC have overall responsibility for ensuring that any research proposals submitted to them conform to approved principles and conditions. Bell (1999) notes that many professional organisations have strict guidelines including

issues such as deception, encroachment on privacy, confidentiality and safety. Additional, but nevertheless important requirements, for example, patience and empathy are often required when coming into contact with potentially vulnerable participants.

The ethics application for this study was initially submitted in April 2004. The application procedure had changed the previous month to meet new European Union Directives (2001/20/ EC) Previous applications had been accepted in paper form, but the new requirement requested all applications to be submitted online. It may be appropriate at this point to explain the information that is requested by the ethics committee, which is quite extensive, but essential in order to protect the welfare and rights of those being researched. Information packs were required for potential participants, which included older people, family members, doctors, and ASWs. The ethics committee requested copies of the letters of invitation, questionnaires, consent forms and a research protocol for consideration.

Bryman (2001) suggests there are some associated risks within all research and I anticipated that some participants, particularly the older person and their respective caregivers, might get upset when reflecting back on their experience of the detention process. Consequently, I felt an obligation to be as honest as possible with all participants and did not withhold any information in relation to my proposed study and the information pack I sent to all potential participants contained a section on the possible risk to participants. I ensured that potential participants were sent all the information they required to help them make an informed decision

about their possible participation in the research study. For some older people possessing the capacity to consent can become an issue. However, in all cases I explained fully the purpose of the research and received their voluntary consent to partake in the research. Research ethics committees emphasise the need to provide accurate, truthful and comprehensive information to all participants. However, Bryman (2001) concludes that the obligation to adhere to the principle of veracity exists throughout the study. Following several amendments, my application was approved with a letter of confirmation. Approval and confirmation was also received from the Research and Development Unit of the South Birmingham Mental Health Trust and the Local Research Governance Committee.

According to Bryman (2001) ethics approval is vital within the research process where vulnerable people are involved, although it proved to be a complex and time-consuming process. Some older people who are users of mental health services become vulnerable and their mental, physical and social circumstances may predispose them to exploitation and Bryman (2001) claims, as a consequence of their mental illness they may need protection, especially where their understanding of the research process is incomplete. Bryman (2001) notes that researchers are dependent on decisions made by ethics committees, but those committees that are primarily set up to protect, but not empower, can both discourage researchers, while disempowering potential participants and concludes that in the final analysis, appropriate ethical behaviour will depend on the respect, the understanding and the concern researchers have for others.

### **Requirement for Informed Consent.**

Silverman (2001) briefly outlines the nature and meaning of informed consent. Accurate information should be provided to potential participants, simply explaining what the study is about and what the participant's role would be within the study. I provided information packs containing details in a manner that were easy to understand, with the aim of helping the participants decide if they wanted to take part in the research study or not. It was emphasised that participation would be entirely voluntary and that withdrawal from the study would be accepted at any time, free from any pressure from researchers or colleagues. As Bryman (2001) suggests,

... subjects should not be under the impression that they are required to participate. They should also be aware of their entitlement to refuse at any stage, for whatever reason and to withdraw data just supplied.

(Bryman, 2001:481)

According to Silverman (2001) the central argument for obtaining consent from participants is that research can often be intrusive and intrusion only becomes legitimate if consent is obtained. This principle applies to more than the research participants - it covers anyone who is the subject of research and not merely those who are providing the information. For example, if one person talks about another person, consent needs to be obtained before any interviews take place with other participants. Within this study, I fully explained to all older people that it was my intention to seek interviews with doctors, ASWs and family members who had been involved in their `case` and consent was obtained. Ethical guidelines stress the

importance of gaining informed consent where possible, although the issues around gaining consent from older people with mental illness remain contentious.

Researching older people with a mental illness, for example, those with cognitive problems can be difficult when attempting to gain informed consent, because of possible communication problems. According to Bartlett and Martin (2002) conducting research with vulnerable people involves careful attention to the interests of the person. As discussed above, although it is understood that informed consent is a necessary prerequisite to research participation, it appears less clear how to proceed when potential participants lack the capacity to provide such consent. In such circumstances, it can prove difficult to communicate to the older person exactly what the research is about and, the purpose of the interview. For the purposes of my qualitative study, I personally sought the advice of those professionals, for example senior ward managers, who were involved in the care of the older person to discuss if they considered the person in question able to take part in my study. Furthermore, I also contacted family members, where applicable, to ensure they were happy for me to talk to the older person. Informed consent is an ethics requirement and, as such, in every case, signed consent was obtained before any interviews took place.

However, the choice of whether to gain written consent is debated in the literature and approaches and attitudes can vary. Pratt and Wilkinson (1997) revisited consent on each occasion they met participants to ensure it remained valid. Bamford and Bruce (2000) undertook an alternative approach, rejecting written



consent in favour of verbal consent in order to minimise the possible anxiety for participants. Bartlett and Martin (2002) suggest that for many people the requirement to sign a consent form might induce feelings of anxiety and insecurity. Informed consent is a process rather than a solitary activity should ideally be tailored to meet individual needs and beliefs (Milton, 2000) The fact that so many researchers do obtain written consent is possibly influenced by LRECs and, more recently, Research Governance Committees, who maintain that written consent, is essential to the research process, which proved to be the case within this study. However, from my experience, the constraints of ethics committees and research governance protocols, whilst necessary to protect all participants, made any degree of flexibility, as described above, hard to achieve.

While gathering data for my documentary study within the medical records department at the Queen Elizabeth Psychiatric Hospital, I simultaneously spent many hours over a period of months observing `life on the wards`. On several occasions, older people who had been detained approached me and asked, "Are you a doctor or a nurse?" Consequently, I always explained who I was, that is a researcher from the University of Birmingham and also confirmed that I was involved in a study that was interested in `people's stories` about being in hospital. It was my intention to be as honest as possible with those older people, who, sometime in the near future, I may be contacting to request their participation in my research study. It was never my intention to deceive people in any covert manner, which would transgress all the LREC and Governance principles, for example, by

not allowing participants the option of refusing to take part in the study. Various forms of contact details were provided to give participants a choice of methods to contact me including telephone numbers, e-mail addresses and home and university department addresses. It was also suggested that it would be completely acceptable for a member of their family to contact the researcher, either for further information, or indeed, to confirm their willingness to take part in the research study. This approach again provides examples of the veracity, fidelity and rigour applied during the course of this study.

### **Justifying the Sample Population.**

According to May (2001) the sample population within a research study is important to ensure validity through adequate representation and also, to aid the development of participants explanations through the interviewing process. The nature of this research study, particularly the research questions, was a prime determinant for the selection of participants to take part in the qualitative element of the study. Purposive sampling was employed for this study whereby a selection of those to be interviewed was made according to certain criteria (May, 2001) Hence, the sample population for the qualitative study consisted of older people who met the criteria of being 65 or over; who had been compulsorily detained under the MHA (1983) and who had been recently discharged from hospital.

Communication mechanisms were put in place with medical records staff and senior ward managers at the Queen Elizabeth Psychiatric Hospital, to inform me when older people who met the criteria had been, or were due to be, discharged

from hospital. I then contacted older people who had been discharged from hospital requesting their participation in the research project; hence the study adopted a timed sample. According to Bryman (2001) time sampling simply refers to the time potential participants are approached requesting a possible interview. Information packs were sent to all potential interviewees including a letter of invitation to family members (Appendix No 2); an information sheet to older people (Appendix No 3) and an introductory letter of invitation to doctors and ASWs (Appendix No 5) A consent form was sent to all participants to be signed and returned if they agreed to participate in the study (Appendix No 4) During interviews with the older people, I asked if it would be possible to also interview a family member, where relevant, to explore what impact detention had on them. Participants were informed they could terminate participation at any time and advised that if they chose to stop, any information they had provided would be deleted and not used for any purpose within this study. As previously stated, all interactions with participants were consistent with policies and procedures within the ethical and research governance guidelines.

To help gather a broader and more balanced understanding of the experience of compulsory detention, interviews were arranged with doctors and ASWs to explore their interpretation of the older person's experience. As the study progressed, several doctors and ASWs were interviewed on more than one occasion, but about different older people who had been detained. Interviews were arranged in venues in which both interviewer and interviewee felt comfortable which hopefully

encouraged older people in particular, to talk about their experiences of being detained. I decided that this would be best achieved by inviting all participants to describe their experience of events in a chronological order that is, prior to the time of the older person's assessment; what happened when they first arrived in hospital; what it was like on the ward, through to the time of discharge.

I allowed participants to raise issues they felt important and not identified by myself. Interviews were digitally recorded if participants agreed and after gaining their informed and signed consent. Gray (2004) states that recorded conversations present more reliable evidence than hastily written field notes and also reflect on the veracity, fidelity and rigour of the chosen research method. However, it is acknowledged that audio recording of certain events may lose some important aspects of social interaction. A postal questionnaire would have been easier and less expensive but according to Gray (2004) there are downsides to adopting such a method for gathering data because the possibility of probing beyond the answer that people give is absent. Additionally, there would be a need to keep questions relatively simple and straightforward as the researcher has no control over how people are interpreting the question once it has been mailed. Importantly, the researcher has no control over who answers and completes the questionnaire - it would have been possible for any family member, caregiver, friend or neighbour to complete it.

### **Pilot Study.**

The pilot study was used as a template to pre-test the qualitative methods of data collection and to determine if the proposed questions and interview approach would be appropriate for this study. It was also an opportunity to verify the time required for interviews and simultaneously identify any necessary amendments to the interview process. As May (2001) states, the meaning of a question may appear clear enough to the researcher, but it does not follow that the older person answering the question will agree with your interpretation. The initial fieldwork helped me understand any concerns of the participants by asking them their opinions on the ordering and types of questions. May (2001) suggests it is important to ask questions that the `target population` will not only understand, but will also possess the knowledge to answer.

Before writing the methodology chapter in its entirety, I had completed the pilot interviews. Interviews were completed with 3 older people, (2 females and 1 male). Volunteers for the pilot interviews were identified over a period of time, as a result of employment I had undertaken at an adult day-centre. It was common knowledge that a high proportion of service users attending the centre had previously been subject to detention under the MHA (1983) some on more than one occasion. In several cases, it had been incorporated into their individual discharge care-plan to attend the day centre which provided me with the opportunity to ask people whether they would be willing to talk to me regarding their individual experience. The initial approach was totally overt, explaining to potential participants, in the

presence of senior staff, the purpose of the interviews while also confirming they could withdraw at any time, or indeed, have a member of staff present during the interview.

Although this pilot study required participants to be 65 or over, only one female and the male interviewee were in fact over 65. The other female was 63 years of age, but the interview served the intended purpose, which was to help establish whether the process was an appropriate research method for the qualitative study. The week preceding the agreed interview date, I provided written information to the volunteer participants to give them time to read what the interview entailed and what they would be requested to do. The interviews were conducted at a social services day-centre, which was attended by all three participants several times a week. On the day of the interview, I introduced myself and proceeded to explain what form the interview was going to take. The purpose of this approach was an attempt to keep the process as close as possible to the “real life” situation, which I thought was important. Interviews were completed within forty-to-fifty minutes and focused initially on personal information, before moving on to questions relating to the older person’s experience of being detained under the MHA (1983) and proved to be most beneficial.

#### Pilot Study Data Analysis and Limitations.

*Because of the small population sample used in the pilot study I have decided to present the analysis here.*

Although just three interviews were conducted for the pilot study, several common themes were identified. It became increasingly clear during the analysis of interviews that all participants were in favour of possible alternatives to compulsory detention. None were happy at being detained in hospital. The main themes to emerge from the pilot study were issues related to exclusion and communication. *“There`s no need to lock us up all the time, but you don`t get a choice”,...”I have a close family who would look after me but no, no chance”, ...” they give you tablets and that`s it, but why keep me in hospital, they could give them to me at home”* were several of the comments made by participants within the pilot study. Two participants also referred to *`not having much to say`* at the time of assessment or during the discharge interview. (Milton, 2000) However, I did not interview any professionals or family members for the pilot study and in hindsight, this may have been a slight weakness, as it would have possibly presented me with *`richer`*, more balanced data and so allowed a more in-depth analysis of the interviews. A larger sample may have provided me with several more themes, which could have been contrasted with those identified within the qualitative study. One final point may have benefited the pilot study. A *`focus group`* interview with all three older people may have made them feel more *`comfortable`* during the interview process and so led to a more open conversation relating to their experiences. Comments may have *`snowballed`* and so provided me with more data. This was a possibility because all three were present on the same day. However, it would not have been practical to carry this forward to the qualitative study because my interviews with

older people took place over several months and at different times and places.

Hence, the pilot study did not lead to any modification of procedures.

### **Summary.**

The aim of this chapter was to explain and justify the preferred methods for data collection and analysis. From the very outset of this thesis, I have understood that the methods of enquiry for collecting data are not just important, but absolutely crucial, if I was to do justice to the research study. The phenomenon under study was the determining factor for choosing a particular method, and not the other way around, because the older person was studied in their entirety in their everyday context. One-to-one interviews allowed me to meet and talk to older people and their caregivers in their natural surroundings. The research questions within this study required a qualitative approach to help demonstrate the variety of perspectives that are essential to gain an insight into the experience of older people who had been detained. Since mental illness is a global issue, a comprehensive understanding requires cooperation and collaboration of multi-dimensional groups. Within this study, professionals represented the coordination and authorisation while older people and their caregivers provided a valuable insight into the practical and real life experience of compulsory detention. Adopting a qualitative approach, particularly for the interview process, is a particular strength of this study. It helped me recognise and understand that personal experiences may be different, because of the different subjective perspectives and social backgrounds related to them. Hence, qualitative



methodology allowed me to explore the phenomenon through the `eyes` of the people who were involved in the process. A further strength was the ongoing examination and analysis of the individual interviews which has advanced our limited understanding of compulsory detention, in what can only be described as very difficult circumstances.

As described above, IPA is a qualitative research approach committed to the exploration of how people, in this case, older people, make sense of their major life experiences. However, according to Smith (2009) experience is a complex concept with the emphasis focused on what happens when the everyday flow of lived experience takes on a particular significance for people – usually occurring when something important has happened in their lives. IPA shares the view that people are sense-making creatures and so the accounts they provide will reflect their attempts to make sense of their experience. However, as Smith (2009) concludes, experience is always dependent on what participants tell us about their experience whereupon the researcher will then need to interpret that account in order to understand that experience.

## ***Chapter 5.***

### **Documentary Study - A Descriptive Profile of the Study Population.**

#### **Introduction.**

The aim of this chapter is to provide a descriptive profile of the study population from which the qualitative sample was drawn. The chapter will also focus on the compulsory detentions of older people (65+) at the Queen Elizabeth Hospital, over a four-year period (2000-2003) and will provide several gender comparisons to provide an insight into the scale of the use of the Mental Health Act (1983) with older people within the study area. Reference will be made to the numbers of older people detained; sections used to detain; diagnosis following assessment and the outcomes following discharge from hospital.

#### **Older People and Mental Illness.**

Mental health and emotional well-being are as important in older age as at any other time of life. Most older people have good mental health, but some may be more likely to experience events that affect emotional well-being, such as bereavement or disability. The Department of Health (DoH) (2005b) estimates that approximately 40% of older people seeing their GP, 50% of older people in general hospitals, and 60% of care home residents, have a mental health problem. Sixty per cent of patients over 65 in general hospital beds have, or will develop, a mental health problem, including dementia, delirium or depression. Depression can increase mental distress and affect an older person's ability to function from day to day. When untreated, depression shortens life, exacerbates disability from medical

illnesses, increases health care costs and is the leading cause of suicide among older people - when treated, quality of life improves (National Institute for Mental Health, 2005) Older people tend not to complain of being depressed but are more likely to refer to physical symptoms, some similar to those of depression. However, physical illness is also a common trigger for depression in older people. Broadly, there are two groups of older people to whom mental health legislation applies: those who develop dementia or depression in later life, and those with 'enduring mental health problems' (people with a life-long mental illness such as schizophrenia or manic depression) Although several studies have addressed issues around the use of the MHA (1983) the biggest, Barnes, Bowl and Fisher (1990) looked at referrals of people across all age groups, not specifically of older people. Nonetheless, one particular outcome of that research highlighted what the authors identified as a high proportion of people 65 and over who had been referred for assessment - 20.3% over the period, with 16.3% of those ultimately detained falling within this age group (Op cit: 151,160) As mentioned earlier, this contrasts with advice from the Mental Health Act Commission (MHAC) (1987) who stressed that when assessing older people, compulsory detention should be used as a last resort.

### **Family Members – The Caregivers.**

Although not referring specifically to caregivers of older people, Oyeboade (2003) states that families of those with mental illness are affected by the situation of their relative. In many cases, family members not only provide practical help and

personal care but also give emotional support in the often inevitable change in the nature of the underlying emotional relationship. Thus, the relationship's usual characteristics are altered either temporarily during an acute episode of illness or on a long-term basis in the case of chronic conditions, and the balance often changes as the parties become the caregiver and the care-receiver. Oyeboode (2003) suggests those who receive care are, necessarily, dependent on their caregiver which can make them vulnerable to the nature and quality of the care provided by that particular person. For the caregiver, the demands not only bring direct stresses but also have indirect effects. For example, taking on a caregiving role may reduce the time, energy and finance available to devote to the other demands of life and this can affect work, social life and other relationships. Nevertheless, caregiving may also have its satisfactions. Providing care and support to a relative is not a static process since the needs of the older person may alter as his or her condition changes. There is continual change and adjustment in the caregiving relationship and the role of the caregiver. Where there is acute disturbance or where care is required on a long-term and intensive basis, many caregivers may need to let others step in to share or take over responsibilities. Oyeboode (2003) concludes it is not surprising, therefore, that being a caregiver often raises difficult personal issues about duty and responsibility, adequacy and guilt. Given the additional energy, time and work that are entailed in providing care, alongside the emotional demands and wider impact on support systems, many caregivers may find the role has a significant impact on their well-being.

Many older people with mental health needs receive help from a family member or friend. Some caregivers are powerful advocates for their relative's right to live independently in their own homes; others do not want to see their relative exposed to risk and feel they should persuade the older person to accept the 'safe' option of residential care. According to Jones (2002) relationships between older people and their caregivers are not always positive, and occasionally there are conflicts of interest between the caregiver's wishes and the older person's best interests. Furthermore, relationships between caregivers and professionals are not always straightforward either. Sometimes professionals take a negative view of caregivers, seeing them as putting their own interests before that of their relatives. At other times some professionals may get drawn into acting on behalf of the caregivers rather than the older person, ignoring the older person and communicating directly with caregivers. This is more likely to happen where there are communication difficulties with the older person. Practitioners' responsibilities will be primarily to the older person with mental health needs, but it is in the interests of the older person that the enormous contribution made by caregivers, often at considerable cost to themselves, should be acknowledged and supported.

**Data Analysis: Compulsory Detentions of Older People (2000-2003) at the Queen Elizabeth Psychiatric Hospital - Making Sense Of It All.**

Similar to many researchers faced with a vast amount of raw data, I encountered several problems during my initial attempt to navigate my way through the data gathered for the documentary study. How would I capture on paper the relevance and importance of the data before me and simultaneously, make sense and give

justice, to all those older people whose experiences I was about to report? It was my intention to provide an insight into the use of the Mental Health Act (1983) with the study population and in doing so, highlight the gender differences.

One particular issue that previous research reported as important is the potential consequences of informal admission. Several studies have focused on informal (voluntary) admissions (eg Hoggett 1996; Prior 1999) rather than compulsory detentions. It is often the case that older people, who are initially admitted to hospital informally, are compulsorily detained following further assessment. Indeed, a substantial proportion of applications relate to patients in hospital, most of them informally admitted (Barnes, Bowl and Fisher 1990) The focus of my study was on older people who had been compulsorily detained under the MHA (1983) hence no comparisons will be made with reference to those referred for assessment and not admitted, or those older people who were informally admitted, unless they were subsequently detained under the MHA (1983) I will consider first the pattern of detentions over the stated four-year period.

YEAR	Total No of Detentions	<i>65 and Over</i>	Under 65	<i>% Of 65 and Over</i>
<b>2000</b>	294	91	203	31%
<b>2001</b>	295	90	205	30.5%
<b>2002</b>	297	95	202	32%
<b>2003</b>	272	94	178	34.5%
<b>Total</b>	<b>1158</b>	<b>370</b>	<b>788</b>	<b>32%</b>

**Table 5.1 - Total number of formal detentions of older people within the Queen Elizabeth psychiatric hospital. (SBMHT) (2000-2003)**

Table 5.1 illustrates the pattern of detentions of older people over the study period. It should be noted that the data refers to the actual number of detentions rather than the number of people, as some older people were detained on more than one occasion during the study period. For example in 2000, 85 older people in total were detained under the MHA (1983) with two being detained on three separate occasions, while a further two were detained twice. Although the total number of detentions of older people was largely consistent over the four-year period, the percentage of older people detained increased gradually between 2001-2003.

Overall, 32% of compulsory detentions within the Queen Elizabeth Psychiatric Hospital involved people who were 65 and over, which is virtually double the 16.3% reported in the Barnes *et al* (1990) study. From the table it can be seen that since 2001, the total number of people under 65 who were detained decreased, possibly as a result of the use of crisis intervention teams in the community, although the same observation cannot be made for people over the age of sixty five.

<u>Year</u>	<u>Section 2</u>	<u>Section 3</u>	<u>Section 4</u>	<u>Section 5.2</u>	<u>Section 135</u>
<b>2000</b>	37	33	2	18	1
<b>2001</b>	35	28	1	25	1
<b>2002</b>	40	33	1	21	0
<b>2003</b>	34	37	1	22	0
<b>Total (%)</b>	<u>146 (40%)</u>	<u>131 (35%)</u>	<u>5 (1%)</u>	<u>86 (23%)</u>	<u>2 (1%)</u>

**Table 5.2 - Yearly comparison of the main sections of the MHA (1983) used to detain older people within Queen Elizabeth psychiatric hospital (SBMHT) (2000-2003)**

The figures in Table 5.2 refer to the initial section used to detain older people under the MHA (1983) and indicate that section 2 was used more often than any other section during the study period. Forty per cent of compulsory detentions came under this section, with a further 35% detained under section 3. There were also instances (23%) over the four-year period where older people who had entered hospital informally and subsequently detained under section 5.2, (doctor's holding power - authorises the detention of a person for 72 hours) were eventually converted to either a section 2 or 3.

It should be noted that the figures reported above are the initial sections used to detain the older person and so it follows, that any detentions under section 5.2 that were eventually converted to a section 2 or 3 would have been additional to the sections 2 and 3 reported above. Although some older people had agreed to enter hospital voluntarily, they may have changed their mind when they arrived on the ward and tried to leave. Doctors may then decide this was not possible because of the older person's mental distress, resulting in a section 5.2 being instigated following which, a further decision has to be made either to make an application for detention under a section 2 or 3 or to discharge the older person because no further treatment is deemed necessary. One important factor is the negligible use of emergency powers under section 4, but this may explain the consistent admission of older people under section 2 and 3 respectively. However, there may be a simpler explanation that some older people may have a mental health history and more likely to be in regular contact with mental health services. Consequently,



emergency detention under a section 4 may be deemed inappropriate. Barnes, Bowl and Fisher (1990:62) also noticed a marked reduction in the use of emergency powers and concluded the decrease may “provide comfort to those seeing the previously higher rate of use of section 4 as an indicator of its abuse”.

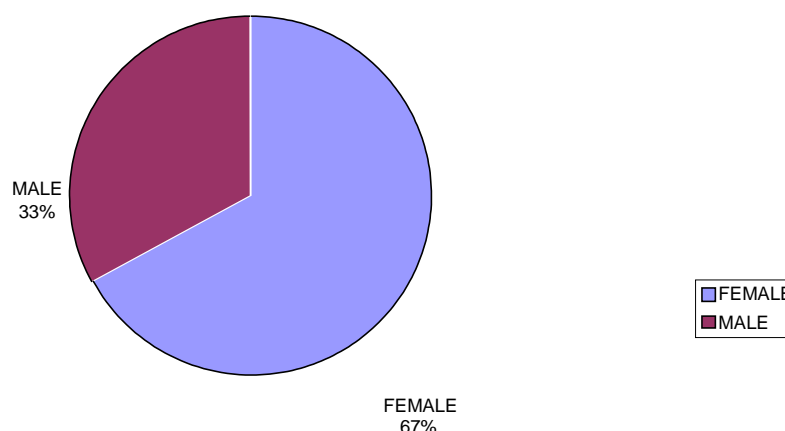
There is an important point to consider concerning section 135 which allows an approved social worker or others to “gain access to a mentally disordered person who is not in a public place and, if necessary, remove him or her to a place of safety” (MHA1983) Section 135 is not a `detention` section per se, but rather, a legislative mechanism to gain access to a person, who may or may not be mentally disordered. This then allows an assessment to take place if necessary, which may ultimately lead to the older person being compulsorily detained under a section 2 or 3. Consequently, it is possible that the section 135s shown in table 5.2 may have been used initially to allow for an assessment to take place, and then an application made that may have resulted in a section 2 or 3 being implemented. The figures reported above only include Place of Safety orders where the Place of Safety was a hospital. Although the figures for section 135 seem rather low and may be viewed as an anomaly, that is, just one section 135 in each of the years 2000 and 2001, when they are compared with the patterns of use on a national scale they appear to be more typical. Data on the DoH (2004) website indicates that every year between 2000 and 2004, less than 1% of `compulsory detentions` were recorded as section 135s. Consequently, it can be seen that although the national figures appear low, they are consistent on an annual basis and as such,

when the reported figures within Queen Elizabeth Psychiatric Hospital are again analysed, they fall within a comparable numerical framework.

### **The Gender and Age Imbalance.**

Gender inequalities relating to mental health have been well documented, with particular emphasis being placed on the over-representation of women in the mental health system (Barnes, Bowl and Fisher 1990; Hatfield and Mohamad 1994; Rogers and Pilgrim 1996; Goodwin 1997; Pilgrim and Rogers 2003)

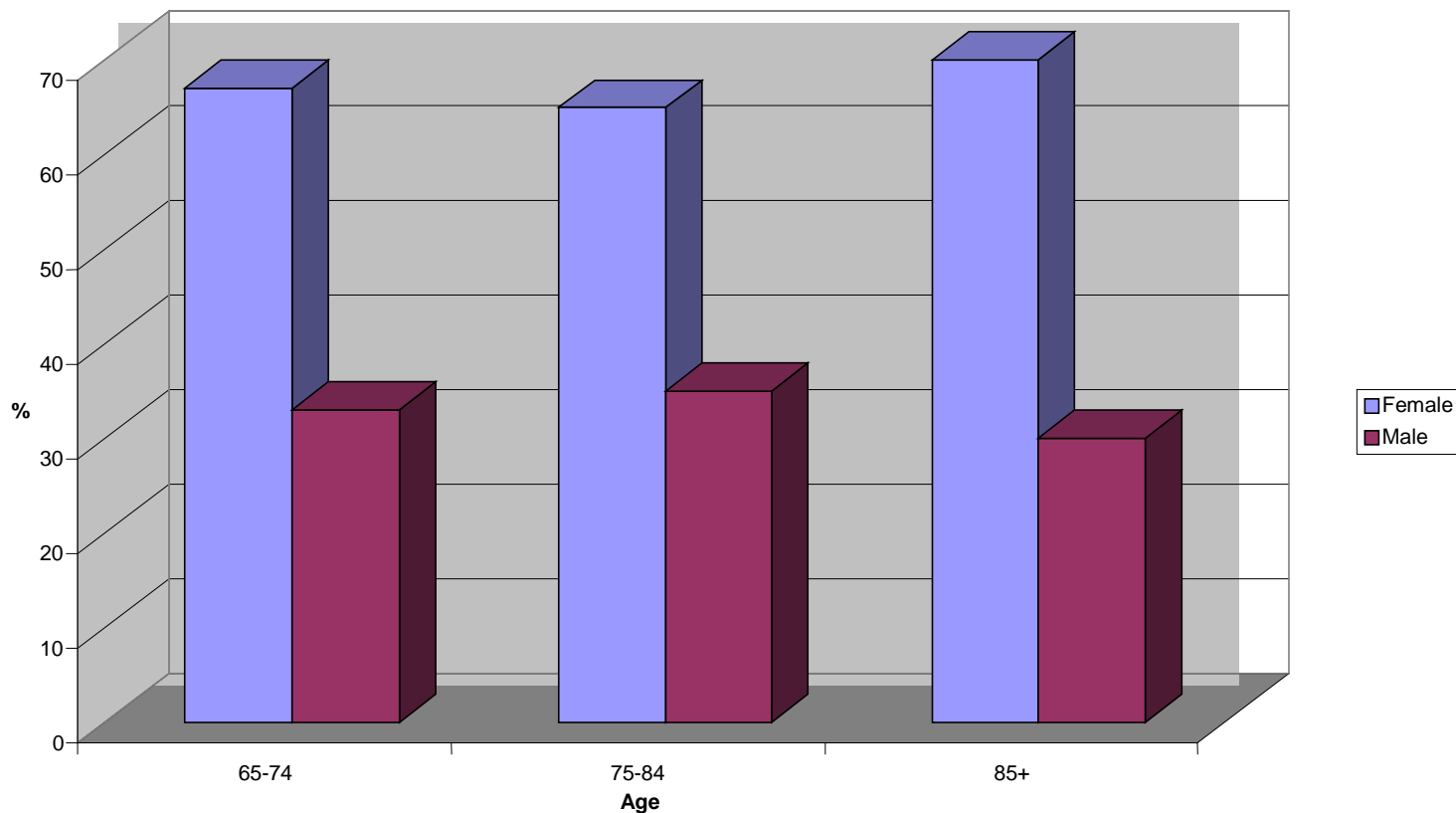
However, more recent data suggests this imbalance is shifting. In 2003-4, 13,402 men and 11,430 women were compulsorily admitted under the MHA (1983) in England (DOH 2004) The available data did not provide an age breakdown relating to sections used to detain.



**Figure 5.1 Gender comparisons of compulsory detentions of older people in SBMHT (2000-2003)**

Findings within this study demonstrated that numerically, a substantial majority of the older people being detained were older women, compared to older men. There were a total of 370 compulsory detentions, of which 253 (67%) were women and

117 (33%) were men (Figure 5.1) These figures would equate to 820 older women and 577 older men per 100,000 population respectively being detained.



**Figure 5.2 - Gender and age groups of older people detained at the Queen Elizabeth psychiatric hospital in SBMHT (2000-2003)**

The greater numbers of older women detained within this study may be a cause for concern, with a far greater proportion of older women than older men being detained across the three indicated age groups, that is 65-74, 75-84 and 85+ (Figure 5.2) The figures of those older people detained do need however, to be considered in relation to the overall population within SBMHT. The proportion of older women detained within the area was 0.82%, while the rate for older men was

0.58%. These calculations are based on data gathered from the Census 2001, which recorded the total population of South Birmingham as 383,000. The total population within the SBMHT for older women (65+) was 30,859 and for older men (65+) 20,275.

**Gendered Comparison of the Living Circumstances of Older People Prior to Assessment and Following Discharge from Queen Elizabeth Psychiatric Hospital (2000- 2003).**

The living arrangements of older people at the time of assessment and discharge from hospital are key factors to be considered. For example, where did the older person live and how many were living alone, or living with others, for example a family member? Additionally, what was the outcome following discharge from hospital? These issues will also be explored during the qualitative element of this study. There are several important points to make relating to Table 5.3 below. It is possible that older people who were living in a nursing home or within residential accommodation may have been living with their spouse or partner, but this information was not recorded. Similarly, those older people who were living in warden accommodation may have regarded it as their own home, but because it was recorded in medical records as a separate category to those living in their `own home`. I have decided to present them accordingly.

**Living Circumstances of Older People Prior to Assessment and Following Discharge from Hospital.**

Proportionally, the pattern of older people resident in a nursing home at the time of assessment is very similar – 40% older women compared to 38% older men while 43% older women and 34% older men were discharged to a nursing home.

<b>Accommodation</b>	<b>Admitted From</b>		<b>Discharge To</b>	
	<b>OLDER MEN</b>	<b>OLDER WOMEN</b>	<b>OLDER MEN</b>	<b>OLDER WOMEN</b>
Own Home	25 (22%)	38 (15%)	6 (5%)	27 (11%)
NH – Res Accom	45 (38%)	102 (40%)	40 (34%)	109 (43%)
Ward Accom	44 (37%)	93 (37%)	32 (27%)	73 (29%)
Inpatient	2 (2%)	18 (7%)	–	–
No Fixed Abode	1 (1%)	2 (1%)	6 (5%)	7 (3%)
Gen - Hospital	–	–	5 (4%)	12 (5%)
Transferred	–	–	15 (13%)	12 (5%)
Deceased	–	–	2 (2%)	3 (1%)
Not Recorded			11 (7%)	10 (3%)
Total (%)	117 (100%)	253 (100%)	117 (100%)	253 (100%)

**Table 5.3 – Where older men and women were living at the time of their assessment and discharged to following detention at the Queen Elizabeth psychiatric hospital SBMHT (2000-2003)**

**KEY:**      NH – Res Accom – Nursing Home – Residential Accommodation  
Ward Accom - Warden Accommodation

Thirty seven per cent older women were living in warden accommodation at the time of assessment, exactly the same proportion as older men - 37%. Fifteen per

cent of older women and 22% older men were living in their own homes at the time of assessment. Seven per cent older women and 2% older men were receiving treatment on an informal basis as an inpatient when they were referred and eventually detained under the MHA (1983) Three older people, 2 women and 1 man, were registered as no fixed abode.

### **Outcomes Following Discharge from Hospital.**

One of the principal aims of this study is to explore the various outcomes of detention following an older person's discharge from a section. An important observation from Table 5.3 relates to figures within the 'warden accommodation' and 'own home' categories. In each case less old people were discharged back to the accommodation from where they were admitted. Over the four-year period of the documentary study, 11% older women, and just 6% older men were discharged to their own homes which may reflect possible family support at home for the older women. This compares with 15% older women and 22% older men who were originally admitted to hospital from their own homes. There is a noticeable difference here, with less than a quarter of men originally admitted from their own homes being discharged back to their own homes - which may require further exploration to explore why it appears more difficult to get older men returned to their homes following discharge compared to older women.

It could be argued that if an older person was discharged to their own home and so return to what they consider a "normal" life, this may act as an indicator of the efficacy of the detention. A decision may have been made by the discharging

doctor confirming that with an agreed and suitable aftercare package in place, the older person is considered well enough to return to their own home and, with appropriate support, resume everyday life in the community. From Table 5.3, it can be seen that more older women were discharged to a nursing home compared to those admitted from a nursing home. Conversely, less older men were discharged to a nursing home than those admitted from a nursing home. Over the study period, similar proportions of older women and older men were discharged to a nursing home or residential home, 43% and 34% respectively. This is similar to the proportion initially admitted from the same accommodation that is 40% and 38% respectively. However the same cannot be said for figures relating to warden accommodation where a very important difference can be observed. Although the same proportion, that is 37% older women and older men were admitted into hospital from warden accommodation, this compares to 27% older men and 29% older women being discharged to the same accommodation. The reasons for this difference may be related to the social circumstances of individual older people. If an older person's mental health has deteriorated or not significantly improved, a family member may have decided to undertake the caregiving role. Consequently the older person may have moved into the family home. Five older people died before being discharged from the section (2 men, 3 women), but the cause of death was not recorded on the available medical records. Table 5.3 shows that 3% of older women and 6% older men are recorded as having no fixed abode on discharge from hospital. However, it may be the case that accommodation had to be arranged following discharge, perhaps as part of a care plan and had simply not

been recorded once the transfer had taken place. Similarly, older people recorded as having been transferred, may have been discharged from hospital and transferred to other wards, including clinical care wards in general hospitals - not necessarily within the Queen Elizabeth Hospital, but within the trust area.

Compulsory detention may indicate a critical point in an older person's life, a crisis from which it may not be possible to recover and consequently, analysis of possible outcomes does raise an important area for further investigation and that is whether the compulsory detention of older people becomes a route to long-term residential care. If an older person was discharged back into the community, this may produce implications for providers of informal support especially that of the principal caregiver - discussed in chapter three. From the older persons' perspective, they may prefer to return home following detention, but unfortunately this may not always be possible for various reasons including the requirement for ongoing support which may not be available. Support may be required from family members, who may have family or employment commitments and so be unable to fulfil a permanent caregiver role.

### **Older People Living Alone at the Time of Assessment.**

Barnes *et al* (1990) reported very different living circumstances for older men and women prior to assessment. Within Barnes study, it was reported that 33% older men were living alone, compared to 55% older women within the same age group, that is 65 and over. Table 5.4 below shows a similar picture with a higher proportion of older women living in their own homes or warden accommodation



compared to older men. However, the proportional difference is less than that reported by Barnes *et al* (1990) If we consider the proportions of older people living alone under categories `warden accommodation` and `own home`, what emerges is a different pattern of circumstances.

	Older Women		Older Men	
	Living Alone	With Others	Living Alone	With Others
<b>Warden Accommodation</b>	42 (45%)	51 (55%)	18 (41%)	26 (59%)
<b>Own Home</b>	26 (68%)	12 (32%)	14 (56%)	11 (44%)
<b>Total (%)</b>	68 (52%)	63 (48%)	32 (46%)	37 (54%)

**Table 5.4 – Household support available to those older people living in warden accommodation or their own home prior to their assessment (THE MOST RELEVANT CATEGORIES)**

Forty five per cent older women compared to 41% older men were living alone in warden accommodation. However there is an important observation to be made here and an interesting difference highlighted by the figures reported in Table 5.4. As reported in chapter one, living alone can be a major contributor to mental distress. However, the greater proportion of older people referred from warden accommodation was living with `others`. This situation was not the case for older people living in their own homes with `others` where less older people both men and women were referred.

### **Diagnosis at Time of Assessment.**

According to Rogers and Pilgrim (2003) receiving a psychiatric diagnosis can be highly stigmatising and may lead to a reduction or even loss of an older person`s

social credibility. However, as discussed in chapter one, from a professional perspective, diagnosis could be viewed as legitimising the process of mental health care. Providing a diagnosis may also provide access to services and the required treatment although for some older people, this may mean time spent in hospital. Kay (1963), cited in Barnes Bowl and Fisher (1990) states that a feature of the diagnostic characteristics of older men and women was that schizophrenia appeared more often as a diagnosis of older women than older men – a similar observation to that made within this study (Table 5.5) Also within the Barnes *et al* (1990:152) study, the “proportion of older men who had a diagnosis of dementia was slightly higher than that of women – 32% compared to 29%”. This pattern is again reproduced in this study, that is, higher proportions of women in every category except dementia – 39% of older men compared to 28% of older women had a diagnosis of dementia – a rather larger proportion.

<b>Diagnosis</b>	<b>Older Men</b>	<b>Older Women</b>
<b>Schizophrenia</b>	11 (10%)	29 (12%)
<b>Bipolar Affective Disorder</b>	7 (6%)	28 (12%)
<b>Dementia</b>	42 (39%)	68 (28%)
<b>Depression</b>	18 (17%)	46 (19%)
<b>Mental Disorder</b>	30 (28%)	71 (29%)
<b>Total (%)</b>	108 (100%)	242 (100%)

**Table 5.5 – Diagnosis of older people following assessment leading to compulsory detention at Queen Elizabeth psychiatric hospital (2000-2003) NOTE: Over the study period, there were 20 cases (9 older men, 11 older women) where a diagnosis was not recorded.**

Within this study, 29% older women and 28% older men were detained with a diagnosis of `mental disorder`, which, until the implementation of the MHA (Amendment) (2007) was a very broad category because of the multiple symptoms it covered. Mood and anxiety disorders, neuroses and substance and alcohol abuse could all be categorised under this wide reaching terminology. Mental disorder was not a diagnosis per se, but rather an `umbrella` term often denoting the requirement for further assessment of a person`s mental health. There may be times when professionals involved in the assessment have a difference of opinion relating to diagnosis. The MHA (1983) Code of Practice states that when there is an unresolved dispute between professionals, they should explore and agree an alternative plan. If necessary and on a temporary basis professionals could agree to a diagnosis of mental disorder, which may account for the reported number of older people being admitted under the category of `mental disorder`, rather than a precise diagnosis. Bowers (1998) confirmed that when professionals had difficulty recognising the dividing line between various symptoms, definition becomes complicated and, as such, a diagnosis of `mental disorder` may have been recorded. Bowers (1998) concluded that diagnosis of `mental disorder` was not only confusing, it also produced a number of ambiguous cases.

Previous research by Sidell (1995) and Rogers and Pilgrim (2003) indicated that women receive a psychiatric diagnosis more frequently than men do with the majority of the difference being accounted for by the higher rates of diagnosis in women of depression. Sidell (1995) confirmed many women live longer than men

do and consequently widows become a significant feature of older populations and concluded the associated loneliness and exclusion from social life caused by the loss of a spouse may be a major factor leading to poor mental health in later life, particularly depression and may be viewed as a function of life events. Additionally, the associated physical health problems age can produce may impact greatly on the older person and as such can take on a greater relevance for mental health.

### **Summary.**

This chapter has specifically focused on the first phase of this research study, the documentary analysis. Over the four year study period, the numbers and proportion of older people within the Queen Elizabeth Psychiatric Hospital who were compulsorily detained was largely consistent year on year. What emerged from the initial analysis is that when the numbers and proportion of detentions are compared, the over-representation of older women requiring mental health services is yet again confirmed (Barnes et al. 1990, Rogers and Pilgrim, 1996 and 2003, and Goodwin 1997) This documentary study has served an important purpose by providing a gendered insight into the social circumstances of older people prior to assessment and following discharge from hospital. Although the data presented does not provide any definite answers, it does alert us to important areas to be explored within the qualitative element of this study. One such observation is the proportion of both older men and women who were living alone prior to assessment – a possible antecedent to mental distress.

## ***Chapter 6.***

### **Multiple - Perspective Interpretation of Individual Experiences of Detention.**

#### **Introduction.**

The structure of this chapter follows that of previous chapters whereby I will present case studies from a multiple - perspective to allow individual `voices` to be heard. All names have been changed for confidentiality. At the end of each `story` I will identify the key themes that emerge from the interviews related to each older person. The interview format was not rigid; there was no uniform approach. Rather it required a flexible and adaptable approach to meet the needs of participants. On occasions the older person was interviewed first but at times it was necessary to interview professionals first to meet their availability. However, this did not detract from the aim of the interviews – to maintain a focus on the essence contained within the research questions. The main themes to be explored during the interviews were the participants –

- Experiences prior to assessment
- Experiences of assessment
- Experience upon arrival at hospital
- Experience of time spent in hospital
- Experience around the time discharge

An acknowledgement to the candidness, openness and honesty of all participants is appropriate – at times in quite difficult circumstances which has provided a better understanding of the phenomenon under investigation. However, there is an

important observation to be made relating to the input from some older people during the interview process. Older people, particularly those with a diagnosed mental illness, are a vulnerable population, who, as a result of possible trauma, may be left with reduced capacity and a low level of functioning. I interviewed several older people following their discharge from a section, not necessarily from hospital, and it is clear, that for a combination of reasons, their responses to my questions were, at times, limited which has resulted in their `voice` not being as strong as other participants, possibly reflecting the difficulty entailed in conducting such interviews. A further acknowledgement is required – none of the sample had a diagnosis of dementia although some may have had a degree of cognitive impairment alongside psychosis, depression or other `functional` mental health difficulties. The interviews that follow are not presented in their entirety because some responses were not directly relevant to the research questions.

### **Harry's Experience.**

Harry is 84 years old, has two daughters, Jenny and Alison and a son Robert. I interviewed Harry alone at his council flat: his daughters together at his flat with Harry present and Consultant Psychiatrist John Sands and ASW James at the Queen Elizabeth hospital. Harry seemed a little nervous and at times confused during the interview although eventually a narrative flow was established. Harry's initial assessment took place at his flat, followed by further assessment at hospital following which he was detained under Section 2 of the MHA (1983) (**Harry's transcription - Appendix 6**)

### **Harry's Interpretation.**

How did you feel before your assessment?

... there was nothing wrong, but I had to `go in and get my head done` - I was abusing my wife, well not abusing, I have never abused anyone in my life - we were disagreeing all the time, arguing over this certain third party, who I think er, (long pause) she should have nothing to do with, they said it was all fantasy

Can you tell me about your assessment?

... it took place here in my flat. I went from here to the Q.E. - the er, (pause) hospital in an ambulance, they made me go - there were questions, I didn't know what they were talking about, next thing I'm in an ambulance, and er (hesitating) off to the QE

What happened when you arrived at the QE?

... I had been in Selly Oak first, then went home, then all hell broke loose, a right 'hullabaloo', I was told I was going to the QE - but I was just left, no one spoke to me I wanted to come home, but they, er, (thinking) would not let me,

How were you treated in hospital?

... I saw a doctor, I think he was a consultant and he examined me, but I don't know why I was in there, (rather loud) there was nothing wrong - I shared a room with four other people during the day, one, er, er, coloured guy, there was nowhere to go,

How did you get on with the other patients on the ward?

... got on my nerves a bit, spoke to me now and again, passes the time but I er, (sigh) just kept to myself, that's best I think

What about the staff on the ward?

... some were difficult to, er get on with you know, to talk to, they helped if you asked, otherwise they left you alone, and the doctors, (laughing) they were a waste of time, I kept telling them I was OK, but they wouldn't listen - kept giving me tablets

What happened at the end of your stay in hospital?

... I was told I was going home, I, er, was told I was finished and that was it (pause, thinking) er, my wife was here, my daughters came around - they took care of me - since my wife died I get the er, meals at dinner time, the girl brings them

Do you feel the treatment you received in hospital helped?

... no, there was nothing wrong with me, my, er, girls told me I was bad and I had to behave myself, I had never been bad before, always talking about my head but I didn't feel well - it was all the tablets they gave me (long pause) - they made me feel worse

Why was that do you think?

... I was on the wrong medication, I kept telling them, but nobody listened

How have these events impacted on your family?

... my wife has died now, my daughters have been upset, but I think it was down to them I ended up in hospital. There was something going on, I don't know what but they had something to do with it, me going in hospital (fairly loud)

If you felt unwell in the future, would you go into hospital again?

... no, I would never go near them again, I was OK before I went in, nothing wrong with me, but when I came out, oh God, I was terrible, no never again

### **Caregivers' Interpretation.**

How was Harry before his assessment?

... the twelve months before his (looking at Harry) assessment had been traumatic and, erm, at times, he became threatening to all who knew him, including family and friends (long pause) - things had been tense for a while since he was prescribed medication to try and calm him down – I'm not sure if he was taking it

... mum phoned and asked me to come around straight away. I picked up my sister - when we got here, we couldn't get in; (sigh, pause) he'd barricaded the front door to stop mum getting out (shaking head) We could hear him shouting - in the end we had no choice but to phone the police and our doctor

(Jenny)

What do you think caused this behaviour?

... he kept saying mum was (sigh) seeing someone else - which was completely untrue, (silence) but we have talked about it and, er, well, it's caused all this, it's just a mess (very hesitant)

(Alison)

What happened during the assessment?

... the police arrived around the same time as Dr Sands and he eventually agreed to let us in, – the doctor asked us to leave the room so he could speak to him alone - we weren't happy but went along with it - we went into a bedroom because he was very agitated

(Jenny)

Is that the way things turned out?

... well yes, erm, (pause) we tried to persuade him to go to hospital, we said we would come to, he started shouting and telling us all to stay away (shaking head) in the end he was forcibly removed, put in an ambulance and taken to hospital ... we agreed he needed time in hospital for treatment and were told he might be



kept in following assessment - but when we were getting ready to go with him we were told it would not be a good idea and to allow him time to settle in and visit later (sigh) – we were not happy

(Alison)

What happened on arrival at hospital?

... we weren't told very much really - we found ourselves knocking on doors and ringing people to see what was going on (pause) you know, how long he would be in – I expected more information, not only about dad, but also about mum

(Jenny)

How was Harry treated in hospital?

... the whole experience was not very welcoming – no one told you anything unless you asked - once he appeared unwashed and to be quite honest, dirty. We complained to staff, who insisted he had been washed - but we gave him a bath

(Alison)

What happened at the time of discharge?

... we simply received a phone call from the hospital saying he was coming out of hospital — my immediate thoughts were about mum - how would she feel, would she cope, but no one asked what we thought – but in the end, we had to take turns looking after him, mum couldn't do it

(Alison)

How has the whole experience impacted on your family?

... mum was taken ill and admitted into hospital - three weeks later she died - she just gave up - she could not cope anymore – the previous months had taken their toll and left her physically weak and she found it difficult to come to terms with all that had happened - before dad went in hospital we accepted the situation, mainly to protect mum - she would suffer if we said something to him about his behaviour

(Jenny)

### **Professional Interpretation.**

How was Harry prior to his assessment?

... I have spoken to Harry's daughters and they tell me there were major problems at home – he had threatened his wife more than once and in the end his behaviour got too much for them – he had locked him and his wife into their flat, his daughters rang the police and he ended up in hospital

(Dr Sands)

How was he when he arrived at hospital?

... not happy – shouting at everyone mostly his wife he blamed her for everything  
– he kept saying there was nothing wrong, he didn't want to stay in hospital  
(James)

What happened during the assessment?

... Harry had no insight into his condition and, er, er he lacked the capacity to make any decisions and refused to enter hospital informally - This was absolutely necessary (slight pause, thinking) to er, help assess what was going on both physically and mentally to help form a treatment plan  
(Dr Sands)

What was the outcome of the assessment?

... Harry was suffering from a mental disorder that warranted detention in hospital - there was no alternative because of his lack of insight, refusal to take prescribed medication and the inability of Emma to care for him at home - he refused to enter hospital informally, he did not have the capacity  
(Dr Sands)

How was Harry on the ward?

... as far as I know, er, Harry was well behaved and co-operative on the ward. He mixed well with staff, and er, (pause) other patients, and as far as I know he was fully compliant with his medication  
(James)

Was the right decision made to admit Harry into hospital?

... well, (pause) Harry was eventually considered for discharge back home because of his improved condition. His mental condition had become stable and he was far more amenable to accepting care and help at home, so erm, yes, I think it was the right decision  
(Dr Sands)

... certainly, from what I have been told, Harry was a danger to himself and his family, he wouldn't take his medication and he refused to come into to come into hospital voluntarily so you are left with little choice  
(James)

What was the outcome following discharge from hospital?

... I had only recently been approached about accepting Harry's case, and he had erm, already been discharged. I immediately contacted his two daughters and asked could I call around to see them – which I did  
(James)

What happened when you went to see them?

... Harry was very quiet and both his daughters were not happy, you probably know their mother was not well – in fact she died a while later, but I did arrange quite a bit with this in mind, er, you know, extra support and meals on wheels, but Harry hardly said a word, he wasn't interested  
(James)

### **Key Themes.**

Several themes are identified particularly the power of professionals both at the time of assessment (p 166, 167) and at the time of discharge from hospital (p167) reflected by the exclusion of the older person and caregivers through lack of communication. Harry's expressed denial (p 164,165) confirmed by James (p 168) and his behaviour (p168) particularly prior to assessment, were also common themes. Harry also refused to enter hospital informally (p 168) but returned home following discharge (p168)

### **Charlotte's Experience.**

Charlotte is 76 years old, widowed, lived alone in her own home and had a mental health history dating back to 1974, resulting in detention on several occasions. I interviewed Charlotte alone on the hospital ward while she was awaiting discharge. She was very loud and quite animated which affected the flow of the interview. I interviewed her youngest son Steven by telephone because he did not live in the area and Dr Robert Wright and ASW David at the Queen Elizabeth hospital. Charlotte was initially admitted informally, but after repeatedly trying to leave the ward, she was detained under a Section 5(2) of the MHA (1983) Charlotte was further detained under a Section 2 for further assessment and then a Section 3 of the MHA (1983) followed.

### **Charlotte's Interpretation.**

How were you before your assessment?

... assessment, what assessment, I don't think I had one, there was nothing wrong, I was fine - I'll tell you what though – (hesitant, but loud) don't know who they were, except Wright was there, they just turned up and barged in without a bye or leave, sat down, I didn't like it, and you wouldn't, your wife wouldn't, I was really upset and angry, my husband has passed away and my sons are not happy I'm in hospital

What happened during your assessment?

... there was so much going on, I couldn't understand but I'll tell you something else - I was kidded a bit, the nurse said she was taking me for a drive in her car - before long we were at the hospital – I wish I could see my sons

How were you treated in hospital?

... terrible - I wasn't happy - shouting, I let them all know – I wanted to go home but they wouldn't let me, my sons are not best pleased me being in hospital- they will help me and I have a friend who comes in every day to see me – so why can't I go home, can you see someone for me?

How were staff on the ward?

... useless, I, I kept asking them to help me so I can go home, I just want to go home, can you help me, can you talk to someone for me, please? - There is no way I would trust them again, never, (head in hands) after the way they have treated me, that Wright and all the others.

How did you get on with the other patients on the ward?

... I stayed away from them, none of them could help me so that was that – I didn't talk to them, if they talked to me I walked away – I wasn't interested.

Has anyone talked to you about being discharged yet?

... no and er, er, well yes, one of the nurses said I am going out – but I just want to go home – I live alone but where else can I go, I have a lovely home - there was no need to keep me in hospital.

### **Steven's Interpretation.**

*I interviewed Steven over the telephone because he had moved away from the local area. He was quite forthright – before I had the chance to ask a question he said,*

... I do not like my mother - she caused many problems over the years but if I do not take on the responsibility, no one will. My two brothers will not help – no way My wife asked me not to get involved because she knows what went on years ago - but I had to - I was losing sleep over it

What has caused the trouble in your family?

... we were all taken into care at a young age and, erm, - there was always trouble in the house, you know between mum and dad, always arguing and fighting - the family broke down completely – my er, eldest brother John refuses to have anything to do with her – he has not been in touch for years - David emigrated to America after getting married - he has been contacted but he won't come over

How was your mother before her assessment?

... I've been told she was not taking her medication which posed a risk to both her physical and mental state – looks like they were right

What happened at your mother's assessment?

... I wasn't there but I believe Dr. Wright was there and a social worker - a nurse was at the house trying to get her to go to hospital, but she wouldn't go - I've been told she was aggressive from the moment she arrived in hospital

Why do you think it was necessary?

... well again, it's only what I have been told but my mother repeatedly refused help from carers who visited her every day and apparently, they suspected she was not taking her medication, they contacted social services who then arranged an assessment

How did you feel about your mother being in hospital?

... she was in the best place and, although I don't visit, I do ring and find out what's going on – but no, er, I have no objection to her being in hospital - under the circumstances, it's the best place for her. They don't keep in touch but whenever I ring they are always very professional and helpful

How was she treated in hospital?

... well she would complain about everything and everyone so, erm, if you listened to her, she wouldn't have anything nice to say about them - they do a good job, it must be hard work, I would certainly contact them again if I had to

What will happen when your mother is discharged?

... I was simply told she can't return home – that was it really, she wants to, but erm, she can't look after herself, I can't do it – even if I could I wouldn't anyway, (pause) there is no one else, she has a neighbour who goes in but that's about it – when I spoke to someone on the ward, they said they were trying to get her into a nursing home – that's what she needs now – she can't go back home

## **Professional Interpretation.**

How was Charlotte prior to her assessment?

... there was a chain of events I believe – a neighbour had rang the police and told them she was outside her house shouting and swearing, the police may have known her because I believe it was not the first time they had been called - there was also problems with medication.

(Dr Wright)

How was Charlotte when she arrived at hospital?

... we needed to get Charlotte to hospital for further assessment – but there were problems getting her there, when she eventually arrived she became very angry and aggressive

(Dr Wright)

... she was really angry and shouting at everyone – she was saying she wanted to go home – she tried to leave at every opportunity and lacked any insight into her condition

(David)

What happened during the assessment?

... Charlotte had been involved in a serious road accident earlier in the year and received serious head injuries – it's possible she had a mild degree of cognitive impairment prior to the injury - at the time of her assessment she had significant cognitive deficits and lacked capacity – she would not enter hospital informally so we had no choice but to formally admit her

(Dr Wright)

... Charlotte described having conversations with the television, which had been witnessed on several occasions by carers and also referred to visits from her dead mother which was probably indicative of some visual hallucinations

(David)

How was Charlotte on the ward?

... her behaviour was initially characterised by anger, verbally aggressive outbursts and repeated attempts to leave the ward - but eventually she settled onto the ward extremely well and was totally compliant with her medication which significantly reduced her psychotic symptoms and delusional beliefs

(Dr Wright)

Is Charlotte ready to be discharged?

... yes, but the only help Charlotte will accept at home is from a neighbour, who she refers to as her `man-friend` (pause) There are suspicions she has become increasingly vulnerable to the input offered by him - there is a general belief that he is possibly abusing Charlotte, both financially and sexually

(Dr Wright)

### **Key Themes.**

Charlotte lived alone. Behavioural problems were identified both on arrival at hospital (p 172) and during her stay (p 172). Charlotte was also in denial of any mental distress (p 172) and refused to enter hospital informally (p172). Lack of communication at the time of discharge was also evident leading to the exclusion of Charlotte's perspective relating to the care plan following discharge reflecting the dominance of the professional perspective (171).

### **Michael's Experience.**

Michael is 82 years old, lived alone and has never married. He has a younger sister Muriel and a nephew Tom. I interviewed Michael alone on the hospital ward while he was awaiting discharge and talked to both his relatives in their homes. Michael was a little agitated but spoke very well and was forthright with his views which aided the flow of the interview. I also interviewed ASW James at a psychiatric unit in Aston and Dr Brian Roberts at the Queen Elizabeth hospital. Michael was diagnosed with *'hypomania and non-compliant'* and detained under Section 2 of the MHA (1983).

### **Michael's Interpretation.**

How were you before your assessment?

... I live alone - I'll be honest with you - I don't like people coming into my flat – so (pause) I er, told them to stay away – I was ok, there was nothing wrong with me except for an eye problem caused by an accident thirty years ago, I'm partially blind but I don't need anybody, I can look after myself (hesitated for a while)

What happened next?

... I'm not sure - people were at my flat, banging on the door, I wasn't going to let them in - they shouted it's the police, so I opened the door, next thing there were people in my flat – I was taken to hospital - I'm sure my sister contacted them

What happened when you arrived at hospital?

... (laughing out loud) nothing, no one spoke to me, I wasn't told anything - they tell you nothing, just kept in the dark, fed medication to keep you quiet, it's all poison - I'm not happy - I am always kept in against my will

Do you remember your assessment?

... I don't think I had one – I don't remember – there a waste of time, they just do what they want – you have no say – I wanted to go home but they wouldn't let me

What is it like on the ward?

... the staff have a job to do, but I stay in my room and play music - I stay out of the way, and don't mix with the rest. Some staff are OK, but not all. Whenever I ask for anything, they say they will get back - but they never do

How do you get on with the other patients?

... I don't bother with anyone – I stay on my own, I like it that way, I've been living on my own for years, so I am used to it, I see people when I go for meals, but that's it, it gets really noisy at times, people shouting, so I er, I stay away

Do you feel better now after your stay in hospital?

... no ...no, (drawn out) I'm just the same, there was nothing wrong when I came in I told you that before – but they er, they still kept me in, you don't stand a chance

Has anyone spoken to you about possible discharge?

... no, they're sorting something out, why is it taking so long – why can't they let me go back home, there's nothing wrong with me, so, er, why am I still here

### **Family Interpretation.**

Could you tell me a little about Michael?

... Michael is a very intelligent man, did well at school and had a wide and varied range of interests, he was better than me at school, but his life has been wasted - always in and out of hospital

(Muriel)

How was Michael before his assessment?

... he was living in warden accommodation and I presume one of the staff contacted Michael's GP - he thinks it was me, he shouted at me, but it wasn't - his flat was not fit to live in. When Michael refused to let carers into his flat they contacted his GP who contacted the police and they called for an ambulance – we were told he was not taking his medication

(Muriel)

What happened at Michael's assessment?

... we weren't there – we went to the hospital afterwards - Michael was not very co-operative, he gets so impatient and erm, you know angry – he does not help matters he was forced into an ambulance and taken to hospital

(Tom)



How was Michael when he arrived at hospital?

... we were told he was shouting and wanting to go home - but he couldn't stay in his flat, his neighbours were not happy with him, there was no choice - we can't take care of him – he's really hard work

(Tom)

How was Michael treated in hospital?

... he's not a good mixer - he just keeps himself to himself - we didn't go in that often maybe weekends, I am not very well myself – but he was always on his own he loves his music -when he first went in he caused trouble – he was treated well

(Muriel)

What about Michael's discharge plans?

... the housing association, who own the accommodation where Michael has been living for the last four years, are not allowing him to move back because of his behaviour and he er, can't take care of himself, everyone knows about their decision except Michael, I think it's wrong

(Muriel)

... I often wonder if Michael suspects something is wrong - he was re-graded informal weeks ago and in the past he was allowed to go home -so why not now?

(Tom)

Will you keep in touch with Michael when he is discharged?

... oh yes, we will go and see him – but in the short-term, maybe hospital is the best option until they sort something out

(Muriel)

### **Professional Interpretation.**

What were the circumstances leading up to Michael's assessment?

... there were several factors - self-neglect, lack of personal care and non-compliance with medication. Michael was not eating, not washing and when carers called he was verbally and physically abusive

(Dr Roberts)

... Michael had been troublesome for some time and we had been getting regular reports of him being aggressive to the carers who went in daily - He refused all offers of help saying there was nothing wrong, he was really verbal - in the end we had to call for the police. Michael was taken from his home kicking and screaming

(James)

What happened upon arrival at hospital?

... Michael was causing problems and telling us what he thought about being forcibly brought into hospital. He was not happy – not happy at all  
(James)

What happened during Michael's assessment?

... Michael was showing aggressive behaviour, hypomania with pressure of speech with flight of ideas. His condition had deteriorated - he does not comply with medication and denies he had any medical or mental problems. He did not possess the capacity to agree to voluntarily admission  
(Dr Roberts)

How was Michael during his time in hospital?

... once Michael had settled on the ward and we had stabilised his condition, he was well behaved and quietened down - when he first came in he was shouting and aggressive, - but it did not take long to settle him – he became fine with his medication but most of the time he stayed in his room  
(Dr Roberts)

Has his stay in hospital helped him?

... without a doubt - Michael's stay in hospital has been beneficial, the treatment he has received has certainly stabilised his condition and contributed to the decision to discharge him from hospital  
(Dr Roberts)

What is the current situation with Michael's discharge plans?

... Michael is unaware of the unfolding situation – it's difficult but he will be told when suitable accommodation is secured. He is not being allowed back into his previous home because of a decision made by the housing association and not related to any clinical decision made by doctors  
(James)

### **Key Themes.**

Michael lived alone and was in denial of his mental illness (p 173, 174) – a point confirmed by the professionals (p 176) and would not enter hospital informally (p176). He was also non-compliant with medication and his troublesome behaviour was also identified (p176) He did not remember anyone speaking to him following his arrival at hospital - similarly at the time of discharge (p174) - he was again excluded from discussions relating to his proposed care plan following discharge.

### **Josephine's Experience.**

Josephine is Irish, 72 years old and lived with her sons, John and Peter who I interviewed together at their council home. I interviewed Josephine on the hospital ward where she remained informally awaiting a care-package to be put together before being discharged. A member of staff sat in with us at Josephine's request. Josephine was visibly distressed and quietly spoken. I had to be very patient, often repeating questions in a different manner which disrupted the flow of the interview. She kept her answers short and consequently her input is rather limited. I also interviewed Dr. Brian Roberts and ASW Graham at the Queen Elizabeth hospital. Josephine was detained under a Section 3 of the MHA (1983) because of her "*paranoid delusions, lack of insight and refusal of any treatment*".

### **Josephine's Interpretation.**

How were you before your assessment?

... it's difficult to remember (holding nurses hand, glancing at her) I've two sons at home, they look after me, John is not well himself - he's been in hospital

Can you remember arriving at the hospital or your assessment?

... no, not really – I'm sorry (looking at the nurse, who was going to answer for her – I asked her not to) erm, I know I was in another hospital before I came here, your better talking to my sons – they will know

How have you been in hospital?

... I've been ok – my sons come into see me, but I get frightened - someone threw a cup one day, and er (looking at nurse) I didn't like it did I (hesitant) I don't eat the food, I don't like it, my sons bring me something in – what happens now – will I go back home (nurse shaking head but saying nothing)

How have the staff been?

... oh they've all been marvellous – couldn't do more, especially (name – nurse sitting next to her) she really looks after me, don't you (name) she is always there for me, I like it when she is on, but the rest are ok.

Has anyone mentioned anything about discharge to you?

... pardon – do you mean am I going home?

Yes – has anyone talked to you about leaving hospital?

... no, no I don't think so, I can't remember ( nursing is nodding her head to me - indicating yes) have they (name) – I'm not sure, have you spoken to my sons – they will tell you.

**Caregiver's Interpretation.**

What were the circumstances prior to your mother's assessment?

... she had not been well, not well for a long time, we were ringing our doctor asking for an assessment. She would not eat, drink or take her tablets - imagining all sorts of crazy things were happening to her. She thought we were poisoning her and we demanded something be done  
(John)

What did you do?

... we recognised the signs - we had seen them before and that's the reason for our calls to the doctor. Eventually she was admitted - but to a general hospital, (loud, banging hand on arm of chair) - we couldn't believe it. Nobody listens  
(Peter)

How did you feel?

... we weren't happy - she was taken to a general hospital but thought it would be the first step to getting her into a psychiatric hospital. We thought, well ok, when she gets into hospital they will see the problems and get her assessed  
(John)

What happened next?

... I found out Dr Roberts had phoned the hospital to do an assessment - how can you do an assessment over the phone - it's impossible? - we went to the hospital and ended up arguing with the staff and were asked to leave. We refused and I said, you can call security, do what you want, but we are not leaving until something is sorted  
(Peter)

What happened at the hospital?

...calls were made and a meeting was arranged with Dr Roberts, social services and the social worker - we were happy presuming something would be done. The meeting took place the following week and we were not going to leave until a decision was made to take mum into a er, you know, a mental hospital - that's what she needed  
(John)

What was decided at the meeting?

... my mother needed urgent assessment and Dr Roberts confirmed that her health was at serious risk because of her refusal to eat, drink or take medication

What happened at the assessment?

... they decided to transfer her to a psychiatric hospital where she was eventually admitted – she didn't know what was happening though - there were a few teething problems - they forgot to take her medication from the general hospital and I ended up going down, picking it up and taking it over to the ward

(Peter)

How was your mother treated in hospital?

... well, on two occasions we found dirty washing in her room and ended up taking it home to save any arguments - I mentioned it, but the staff said Josephine got upset if she saw them going through her things, so they thought it best to leave it. Anyone with a bit of sense would have gone into her room when she was out, got the clothes, washed them and took them back

(John)

What happens now following discharge?

... while mum has been in hospital, I have accepted an offer to exchange houses within the area. The house we had was far too big and so I exchanged for a ground floor flat, which is more suitable

... dealing with social services has been an absolute nightmare, they don't keep in touch. We won't allow her to be put just anywhere, we'll hold out for a suitable place

(Peter)

### **Professional Interpretation.**

What were the circumstances leading up to Josephine's assessment?

... Josephine had been in and out of hospital for a while. As far as I know, one of her sons was taking care of her and he's not in good health, her sons became troublesome, and at times er, really angry with staff – to cut a long story short there was a meeting which resulted in Josephine having an assessment, which led to her being detained in hospital – she would not agree to come in voluntarily

(Graham)

What happened on arrival at hospital?

... she was confused, quite perplexed and insisted her food had been poisoned with dope and heroin. We asked her to come into hospital informally – but she did not have the capacity to make a decision

(Dr Roberts)

What happened during the assessment?

... she had no insight, Josephine kept trying to leave and was accusing people of all sorts of things – she refused to enter hospital voluntarily – we er, asked her a few times, but she er, did not understand – we had no choice but to detain her

(Graham)

How was Josephine's behaviour while in hospital?

... she was suspicious while on the ward and having active auditory hallucinations  
- she received ECT as part of her treatment but it took time to settle her down

(Dr Roberts)

... Josephine kept going to the staff room believing people were locked in there - she would stand by the door waiting for a taxi, saying she was being transferred for a heart transplant. She refused to see Dr Roberts, and sacked him as her doctor, saying he had stolen her 3 million pounds worth of savings. She physically assaulted Dr Roberts after accusing him of raping her. There was no evidence to support these allegations

(Graham)

What was the outcome following Josephine's discharge?

... she stayed in hospital for a while, but then she was transferred to a respite centre, where, with the full agreement of her family she stayed, until a more permanent and acceptable place could be found, preferably a nursing home

(Dr Roberts)

... following her treatment, Josephine became noticeably more relaxed - a lot calmer, but there was no way she could have returned home, for one her sons had told us they could not look after her and er, she could not take care of herself, so initially she stayed in hospital informally until we found somewhere for her to go

(Graham)

### **Key Themes.**

Josephine was not compliant with her medication (p178) and refused to enter hospital voluntarily (p 179). Power relationships between professionals and caregivers led to poor communication and exclusion.

### **Valerie's Experience.**

Valerie is 70 years old and lives at home with her husband Peter. I interviewed both Valerie and her husband Peter at their family home. Valerie did not understand that I wanted to interview herself and her husband separately – she kept interrupting when I asked Peter a question and randomly walked off into another room and consequently the interview became fragmented and took a lot longer than expected. Valerie's input is rather limited. I also interviewed ASW Dominic and Consultant Psychiatrist Dr Khan at the Queen Elizabeth hospital. Valerie was detained under a Section 2 of the MHA (1983) suffering from "*severe agitated depression*".

### **Valerie's Interpretation.**

How did you feel before your assessment?

... I don't think I will be much use to you, it's all a blur, I can hardly remember a thing, except for what is happening now

What about when you arrived at hospital?

... Oh, I er, I didn't want to go there, I was scared – there was lots of people and noise, I wasn't happy (gets up and walks out) I'm just checking on a piece of meat in the oven for our tea - what time is it?

Can you remember your assessment?

... no, (really hesitant, stands up) can you remember Peter? I know I've got to go back to the hospital - it's not today though is it Peter?

Do you remember anything about your time in hospital?

... no, oh, oh except for one patient, who you had to look out for, she was always shouting and threw a cup of tea over one of the men one day

How did you get on with the other patients?

... I didn't like them, I was scared – one woman shouted at me one day for sitting in her chair, so I told the nurse – I didn't know (gets up again, Peter tells her to sit down – she does – then gets up again) no, I didn't like her

Did anyone talk to you about coming home?

... no - did they talk to you Peter? (Peter nodded) I remember Peter coming for me with my son – they picked me up - I'm glad I'm home now

How do you feel now that you are home?

... I can't remember much, but I know I was ill, my husband and sons have all told me, but I can't remember much, I'm sorry". I'm glad I'm home, but I don't feel right, but Peter says I am better

## **Caregiver Interpretation.**

How was Valerie before her assessment?

... there had been an attempt to treat Valerie in the community, but without success. Everyone concerned done their best to make it work, but Valerie's condition continued to deteriorate and it soon became obvious that she needed something more - something we could not give her, but it was no one's fault

What happened when you arrived at the hospital?

... she repeatedly asked why she was there. Can we go home now, I just want to go home she would repeat over and over – but (pause) hospital was the only answer, er, although she was not happy she was quiet and did as she was asked

Can you tell me about the assessment?

...yes, no problem - It happened at the hospital. I had contacted our own GP, and he immediately referred her for an assessment. I was happy with it, but Valerie wasn't, she didn't understand why she had to go into hospital – she became really irritable and there were lots of questions

How did you feel when she was detained?

... well what else could they do? - they had tried to treat her at home, so they had no choice, I couldn't take care of her, it was getting too much (Peter tells Valerie to sit down) She's like this all the time

How was Valerie treated in hospital?

... I was not happy with several events. Valerie had a fall while on the ward and we did not find out until we went in and saw her eye was bruised. I asked Valerie what had happened but she could not remember - so I asked one of the staff who said, "*Oh, Valerie had a fall today*". I asked why nobody had bothered to phone me to which the reply was, "*we didn't think it was necessary, it was nothing serious*". "*Nothing serious*" I said, "*she's black and blue*".

What did you do about it?

... I took the matter further and made an official complaint - I received a written apology, - but I made a second complaint. The medication wasn't working and they gave Valerie ECT without informing me - I was angry and my son was furious.



... although we were not happy with the circumstances around the ECT, there is no denying that it, er certainly benefited Valerie. She is not as agitated as she was and she knows who we are now - so much so she is being discharged back home

*(Valerie interrupts - I go back to the hospital every month for a check-up - I am due back on Tuesday, I think - Wednesday, said Peter)*

Did anyone talk to you about discharge?

... I received several phone calls - I wonder if this was because of the complaints we made. I was not happy that Valerie had received ECT without my knowledge, but it was the turning point. The most worrying thing is that we have no idea what caused Valerie's depression so it will be important to watch her in the future to help recognise the signs she attends a group once a week which is a great help, but our lives have changed completely now, especially mine

How has this whole experience impacted on your family?

... I was worried - at the start there was no, er, no light at the end of the tunnel and for a while things did not look good. The medication was not working and each time we went in she didn't recognise us, it was heartbreaking – but although everything has not been perfect, I would not hesitate contacting the hospital if, God forbid, Valerie was not feeling well again

### **Professional Interpretation.**

How was Valerie prior to her assessment?

... Valerie had been depressed for some time, and to be honest a danger to herself and others – it was a really difficult time – particularly for Valerie's husband  
(Dominic)

How was Valerie when she arrived at the hospital?

... she was not very accepting of her situation and at one point, became very aggressive towards her husband – I felt sorry for him  
(Dr Khan)

What about during her assessment?

... during her assessment she was continually feeling anxious and confused. She did not understand why she was there or what was going on - we all agreed Valerie was unable to consent to informal admission because of her lack of insight  
(Dominic)

What was the outcome of the assessment?

... everyone who was there, including her husband agreed that she had to stay in hospital, - but Valerie kept asking her husband to take her home, her husband was visibly upset – which you can understand

(Dominic)

How was Valerie in hospital?

... totally confused – she kept walking around all the ward all day, asking to go home, she did not want to be in hospital – but other than that she did not bother anyone, but she did complain about a few patients

(Dr Khan)

What treatment did Valerie receive in hospital?

... the medication was not working so the only option was a course of ECT – there was no alternative, and it was successful - there was a considerable improvement in her condition

(Dr Khan)

... when Valerie first came in she was put on a course of anti-depressants but they had no effect, and sometimes they don't, the next step is usually ECT – which is what happened and it certainly worked for her

(Dominic)

Did you discuss the proposed new treatment with Valerie and her family?

... Valerie could not understand what we were proposing but we had several discussions with the family regarding the ECT

(Dr Khan)

Can you confirm that ECT did not take place prior to talking to the family?

... yes, definitely not – the family were informed prior to the ECT taking place

(Dr Khan)

What was the outcome of the ECT treatment?

... the outcome was positive – the medication was not working so we tried ECT and it worked – a few days later Valerie was considered for discharge back home which she and her family were happy about.

(Dominic)

### **KeyThemes.**

Power inequalities and exclusion resulting from a lack of communication were present particularly relating to treatment (p182) reflecting the dominance of the medical model. Valerie had identified behavioural problems on arrival at hospital and during her assessment (p183) Valerie returned home following discharge.

### **George`s Experience.**

George is 71 years old and had lives alone in residential accommodation. George did not have a family member I could talk to, but I was able to interview Dr Baker at a psychiatric unit in Edgbaston and ASW Ned at a day centre in Harborne. George had a history of mental health problems dating back to 2002 and on this occasion he had his initial assessment at his home and after further assessment in hospital was detained under a Section 2 of the MHA (1983) “*in the interests of his own health and safety, and also for the protection of others*”. George was relaxed when I spoke to him alone on the hospital ward after he had been re-graded informal and answered questions without hesitation and with confidence which made the interview process flow smoothly.

### **George`s Interpretation.**

What happened that led to your assessment?

... I can`t remember doing anything wrong, but, erm, all these people turned up at my flat, I was a bit scared - they kept asking me to go to hospital but I didn`t want to, but they were going on and on, I can remember someone using the phone

Can you remember the actual assessment?

... I remember everyone being in my flat - I just sat and listened and ended up in hospital, there were questions. (pause) they said I had to stay in, but I said no, no way, I didn`t want to – but they made me

What happened when you arrived at the hospital?

... people were talking, asking questions, I didn`t answer them, I er, didn`t want to, I was told I was being kept in hospital. I just sat there quiet – I said nothing.

How were you treated in hospital?

... It was a bit of a mixture. The other patients were OK, but the nurses and especially the doctors - they have too much power.

What do you mean by that?

... well I agreed to have an assessment but not to be kept in hospital - but I was. The doctors, they make the decision and that`s it. I was never asked what I thought - even now, I am waiting to go out, but no one talks to me about it.

Would you contact the hospital again if you felt unwell?

... no, no way (bit louder) they don't listen to anything you say so why bother  
I'll only end up back in here, so no - I didn't contact them last time, I think it  
was one of my neighbours

Has anyone talked to you about discharge?

... yes, one of the staff has talked to me and said I am going back home and I'm  
happy, but I can't understand why it's taking so long – after all, I've have been  
taking care of myself for years now

### **Professional Interpretation.**

What were George's circumstances prior to his assessment?

... over the previous months George had been displaying strange behaviour -  
spending lots of money on things he did not need. On one occasion when I visited  
him, there were five televisions in one room - two were still packaged. George was  
acting in a very suspicious manner and when I called again the following day, he  
was very aggressive towards me. On the way in, one of the residents stopped me  
and said George had been acting in a very threatening manner and at times, he was  
sexually explicit towards female residents

... because of George's behaviour, I made arrangements for an assessment as a  
matter of urgency - when I returned with Dr Baker, George became verbally  
aggressive and racially abusive shouting - *I don't like you coloured people and I  
don't want to talk to you*

(Ned)

How was George when he arrived at hospital?

... he refused to be admitted informally but had no objection to being assessed,  
he did not want to stay in hospital – he was very noisy - there was absolutely no  
alternative but to formally admit him

(Dr Roberts)

What happened during the assessment?

... George's behaviour was both odd and irrational - there was no alternative but  
to get him into hospital for further assessment. He had no insight into his  
condition - he became hostile and aggressive

(Dr Baker)

... George was acting threateningly and at one point grabbed a walking stick and  
for one moment I thought he was going to lash out and hit one of us – we had to  
call the police - we could not manage it on our own - we thought George would

cause problems but when the police and ambulance arrived, although not happy, he quietly got into the ambulance

(Ned)

Do you believe the correct decision was made?

... without doubt - George`s treatment has been successful - so much so, he is being allowed to return back to his own home

(Ned)

How was George`s behaviour on the ward?

... at first he continued to be difficult but eventually he settled down, he was quiet, although he continually asked to be allowed to go home – but erm, he did mix well with the other people on the ward

(Ned)

So George is waiting to be discharged?

... yes, but unfortunately there has been a delay, but he is being allowed to return to his own home when a suitable care package has been put in place, he has no family to support him

(Dr Roberts)

... yes, I have spoken to George and arrangements are being made for him to return back to the residential accommodation where he was living before he came into hospital.

(Ned)

### **Key Themes.**

Prior to, and during George`s assessment, he was displaying behavioural problems towards residents and the professionals (p186) Professionals stated he lacked insight and refused to enter hospital informally (p186). George returned home following discharge (p187)

### **Katherine`s Experience.**

Katherine is 85 years old and lives alone in her own home following the death of her daughter, who had been her main caregiver. I interviewed Katherine on the hospital ward – she was calm but asked could a nurse be present and I said yes – this helped with the interview. I also interviewed her son Robert at Katherine`s home, Dr Michael Harris and ASW Hayley at the Queen Elizabeth hospital. Katherine was assessed in hospital and detained under Section 2 of the MHA (1983)

### **Katherine's Interpretation.**

How did you feel before your assessment?

... I haven't been well for a long time – I live on my own, hardly go out so I get lonely – my daughter used to live with me, but she died a while back I really miss her - she was very good to me

What happened when you arrived at hospital?

... I remember being told I had to go into hospital – I did not want to – I wanted to stay at home (very quiet) but they would not let me - I wasn't happy

Do you remember anything about your assessment?

... not a lot, I kept looking for my son, I was scared – I didn't know what was going to happen, I think I have been here a while now, not in here, I've been moved – but I'm waiting to go back home now

How have you been treated in hospital?

... I've been treated well – can't complain. The staff always help – but erm some people on the ward are noisy – I don't like that- I'm glad I've moved

If you had to - would you contact the hospital again?

... definitely – I really feel well now, I think I will be going out soon – I'm not sure who rang the hospital this time, I think it was my son, but I have been told I had to come in because of the erm, the way I was

Has anyone talked to you about going back home?

... no – I can't remember anyone talking to me about it, that would be nice. I would like to go home now but I think my son will sort something out – I have not seen him since last weekend so someone may have spoken to him

### **Robert's Interpretation.**

What were the circumstances leading to your mother's assessment?

... my niece said she went around and found her grandmother talking to herself and picking the phone up *`talking to Jim`* - who is my late dad – he died a few years back – she had no idea what she was doing. My niece rang our family doctor who made the arrangements to get her into hospital - social services were involved prior to her assessment - they could have done more

In what way I asked,

...well, with living away, I keep in touch to see how things are, I can't always speak to mum, because half the time, she does not know who I am, but I spoke to carers, but nobody mentioned she had been wandering around outside and leaving doors open, I question their integrity, it's poor, the support was `minimal`, – it's basically short cuts in care - reality is different

What do you mean by that?

... everyone knows about social services, but what services do they provide. In my mind they always arrive late, too late in my mother's case. Why didn't they make contact earlier?

What happened on arrival at hospital and during the assessment?

... I was not present but the ward sister told me mum was shouting a lot - apparently Dr Harris and another doctor were there- and I think a social worker as I say, I wasn't there – but no, it's sort of *Fait Accompli* isn't it?

What do you mean by that?

... well from what I can gather, I feel, and it's only my opinion, their minds are already made up before the assessment and then there is no chance of changing it, that's it, the medical people are so powerful aren't they, they can do what they want regardless of what anyone thinks

How was your mother treated in hospital?

... she was treated really well – she got good care and attention - if I had to, I would call them again. The only complaint is if I wanted to know anything, I had to go knocking on doors

Can your mother go home now?

... no, she is still forgetful but she is strong and eating well – I've just been told she is better, but that's it - just a pity she can't return home where she has lived for so long - not bad though for 85 is it?

### **Professional Interpretation.**

What were Katherine's circumstances prior to her assessment?

... Katherine had been having problems for well over two years but had really deteriorated in recent weeks. She lives alone but there were reports

of her going out and leaving all the doors open  
(Dr Harris)

... prior to her assessment, Katherine had been found wandering the streets by her next door neighbour, totally oblivious to any possible dangers she was receiving support from social services - as far as I know she was happy with that – she had no insight when I went to see her  
(Hayley)

How was Katherine when she arrived at hospital?

... she shouted she was not coming into hospital - she was in urgent need of an inpatient assessment of needs  
(Dr Harris)

... when she first arrived she was not happy, she wanted to go home and kept getting up trying to leave, but once she was on the ward and taking her medication she settled down and behaved really well  
(Hayley)

What happened during the assessment?

... the assessment took place in hospital and she was asked to come in for further assessment but she refused – she lacked any insight into her condition and had become a danger to herself - it was in her best interests – there was really no option but to detain her  
(Hayley)

How was Katherine during her time in hospital?

... at first she was quite troublesome, continually trying to leave the ward and at times disruptive – but once we had assessed her and decided on a course of treatment, she responded and settled down quite quickly  
(Dr Harris)

Can Katherine return home now?

... arrangements are being made to discharge Katherine - she is far more stable now, both physically and mentally, the reason she is still in hospital, is because she cannot return to her own home due to her social circumstances. I believe a placement in residential care is being arranged  
(Dr Harris)

... no, that is not possible - the main problem is that Katherine does not have family in the area since her daughter died two years ago. Her son moved down south years ago following a job opportunity, so it is highly unlikely he will be able to take care of her  
(Hayley)



### **Key Themes.**

Katherine lived alone (p187) – according to professionals she lacked insight into her condition and refused to enter hospital informally (p190). Katherine and her son both expressed times of poor communication (188, 189) which often left them excluded.

### **Rita`s Experience.**

Rita is 70 years old and lives alone in her own home. Her husband had died 6 years earlier, but she had three sons who lived within the area. I interviewed Rita on the hospital ward where she had been for the previous six months. At the time of interview, Rita was anxious and still having memory problems – there were long pauses during the interview and consequently her input is occasionally limited. I also interviewed her son Brian at his mother`s home and Consultant Psychiatrist Dr Roberts at the Queen Elizabeth hospital and ASW Deborah at a hospital unit in Cotteridge. Rita was detained under a Section 3 of the MHA (1983) because of her long standing *psychotic illness – schizophrenia*.

### **Rita`s Interpretation.**

Can you remember the time around your assessment?

... not really, er, no – I was at home, I haven`t been well for a long time though, my son said my er, neighbours had got in touch with him but no, I don`t really remember.

Can you remember arriving in hospital – your assessment?

... (hesitant, thinking) no, I`ve been here for a while - my son said people were at my house, but I can`t remember, I do try, (pause) I think about it every day, one of my neighbours has been in – she said I was shouting outside my house

How have you been treated in hospital?

... oh, I`ve been moved – don`t know why, my son can tell you, but I`m used to being in hospital now (long pause) - I don`t think I will ever leave.

How have the staff been?

... the nurses – er, (thinking, looking around) most were ok but there was one I didn`t like, so I stayed away from her, she wasn`t nice

Did you say anything to anyone?

... er yes – I er (pause) I told, my son when he came in, but I don't know if he said anything – I asked him not to (rubbing hands) I was frightened

How do you feel now following your stay in hospital?

... I just wish they would let me go home - but they say I can't - I feel ok but I'm not eating properly – I don't feel like eating

Has anyone talked to you about leaving hospital?

... no, er - well yes, someone did, it was a while ago now, I can't remember properly now ( rubbing hands, trying to remember) someone said I was being moved, but that's it (looking around, long pause) – I'm not sure now

### **Caregiver's Interpretation.**

How was your mother leading up to her assessment?

... there were problems - I received a call saying my mother was outside shouting and screaming. I went over straight away, but it takes me around 30 minutes to get there, when I got there, the police were there, er an ambulance - my mother was so angry and aggressive towards everyone, I was told there was no option but to get her to hospital for further assessment - I went with her in the ambulance.

So the assessment took place in hospital?

...yes, a doctor was there and a few others

What happened when you arrived at the hospital?

... she didn't have a clue what was happening - my mother needed an assessment to help determine the cause of her behavioural problems - that was fine by me

Were you happy with the way the assessment was conducted?

... yes, but I was in a state of shock - everything happened so fast - phone call, ambulance, assessment, detention - life can change so quickly - she didn't know what was going on, she would not listen and really aggressive

What about your mother's time in hospital – how was she treated?

... well there were problems. On one occasion, she was attacked by another patient and ended up with severe bruising to her body and face. On another occasion, she slipped in the bathroom, banged her head on the edge of the bath and received a gash that required seven stitches

Did you do anything about it?

... obviously, I was not happy - I asked why nobody had bothered to phone me, they said 'we knew you'd be coming in to visit, so we would tell you then' - I put in a written complaint but I'm still waiting for a reply

How has this all impacted on you and your family?

... well, she's in the best place - as much as you want to look after her yourself, there is no way we could have provided the care she needed, and er, I didn't realise the seriousness, but I do now - to be honest, I don't really think about myself, it doesn't bother me what people think – it's more about getting my mother better

Can your mother go back home now?

... no, she can't - she's going into a nursing home but when we found a suitable one, we contacted social services but the care package was not in place - when it was sorted, the place at the nursing home had been taken, so we had to start again. When the funding was in place, we couldn't find a home - It takes time to find one that has a vacancy, it's not our fault. I blame social services, we not going to put her anywhere - after all, it's going to be her new home.

What arrangements have been made while you are waiting?

... I've agreed with Dr Roberts that she can stay in hospital until we find somewhere else - so that's not too bad, to be honest, she is not really over it - but we have talked about it, and feel the best option is a nursing home.

How does your mother feel about going into a nursing home?

... she doesn't really understand – I have spoken to her about it, but you know, the care she needs, there's no choice really - it will be best for her in the long run

## **Professional Interpretation.**

What were the circumstances around the time of Rita's assessment?

... Rita had a mental health history dating back over ten years and had been detained previously – there had been several reports that she was causing problems with her neighbours, and she was also aggressive to anyone who approached her – she was particularly restless, agitated and described hearing voices

(Dr Roberts)

What happened on arrival at hospital?

... absolute chaos – Rita did not want to stay and tried to leave – she was totally oblivious to what was going on – we had to watch her constantly

(Deborah)

What about the assessment – what was the outcome?

... Rita was presenting with cognitive impairment with significant disorientation and had no insight into her mental illness - it soon became apparent that she would require treatment for her long standing psychotic illness - schizophrenia

(Dr Roberts)

... she was quite verbal and physically aggressive – not happy at being kept in hospital saying she wanted to home but there was no way that was going to happen – she wouldn't agree to come in voluntarily – we had to detain her

(Deborah)

How was Rita while she was on the ward?

... she was difficult – staff said she was argumentative, not just with them but with other patients – she would not accept being in hospital - she was attacked by another lady on the ward - when I spoke to her, she knew little about what caused it

(Deborah)

Can Rita return home now?

... that's not possible right now – she lives alone and could not take care of herself, it would not be safe and there would be problems conforming with medication, as far as I am aware we are trying to find a place in a nursing home

(Dr Roberts)

... no – she is awaiting discharge but there is a problem relating to where she can go. She is a lot better now but requires 24-hour care - so she cannot return home

(Deborah)

## **Key Themes.**

Rita lived alone and had behavioural problems prior to and during her assessment (p192, 194). Professionals stated Rita lacked insight and refused to enter hospital informally

(p194). Brian was excluded because of a lack of communication when his mother had an accident (p193).

### **Helen`s Experience.**

Helen is 80 years old but did not have a long mental health history - since her husband died, she had lived alone in her council flat. She had a married daughter Moira, who lived nearby. I interviewed Helen alone at her home following her discharge from hospital and her daughter Moira at her home. Helen was very forgetful and seemed a little agitated which affected the flow of the interview. I also interviewed ASW John and Dr Khan at the Queen Elizabeth hospital. Helen was detained under a Section 3 of the MHA (1983) because of her *severe agitated depression*.

### **Helen`s Interpretation.**

How were you during the time leading up to your assessment?

... I can't remember the (hesitant) exact reasons but I haven't been well for a while – I've not been eating or sleeping

Do you remember what happened during your assessment?

... my daughter told me we were at home, and er, she rang the doctor, I wasn't well my daughter told me that – but I forget what happened, it was so long ago

What happened when you arrived at hospital?

... I'm not sure – you're better off asking my daughter, she will know, she was with me, I don't know, I'm sorry

What about your time spent in hospital – how has that been?

... I am not really sure how long I have been in - my daughter comes in and she has told me what happened – I didn't realise how serious things were, all the staff at the hospital have been very nice, and always willing to help - looking back I am pleased I had the treatment, although at the time I did not know much about it but, it er, seems to have worked

Has anyone spoken to you about leaving hospital?

... someone has spoken to my daughter – she is going to cut her hours in work so she can look after me - I am being allowed to go back home – but nobody has spoken to me about it

### **Caregiver`s Interpretation.**

How was your mother prior to her assessment?

... she had been down for some time, but had noticeably got worse over recent months. She refused to eat, drink or take her medication, I decided to call the doctor

What happened during the assessment?

... mum was not well – she was so confused - it did not take long for the doctor to see that. I must be honest - that they gave her the chance to go into hospital voluntarily but she refused. She knew she was ill, and in the end it was me who talked her into going into hospital for more tests, I took her

What happened when you arrived at hospital?

... she was going on and on about not wanting to go into hospital – we were shown into a room because she was making that much fuss, she was really noisy and wanted to go home, there was no way, she had to stay in

How was your mother treated while in hospital?

... each time I went in there was no improvement – I received a phone call from Dr Khan – he, er explained the medication was having no effect, he said the only way forward was oh, erm the - sorry I have forgotten the name

Electro - Convulsive Therapy?

... yes, thanks – that`s it. I couldn`t remember

What was the outcome?

... things were slow at first, but once they realised the tablets weren`t working things changed quite quickly, she`s back home now, so yes, it`s been good for her

Did anyone talk to you about your mother`s discharge plans?

... yes, they were all very good – mum was so much better after she had the treatment John, the er social worker got in touch and said she was being discharged, he said she was well enough to return home as long as someone would be there for her – I told him I would be here and that was it really, a few days later and she was out of hospital

How has this whole experience impacted on you?

... to be honest, I have not had much time to think about it. I do not have any regrets about getting in touch with the doctor, I had no choice, and my mother knows it was me who contacted him. I mean, what are you supposed to do?

### **Professional Interpretation.**

What were the circumstances prior to Helen's assessment?

... there were reports from the CPNs that Helen refused to eat and I suspect she was not compliant with her medication - she lives alone, no family so it was important to have her assessed, there were problems – her daughter contacted their GP saying Helen was not eating or drinking and also she had been down for several days - she refused to let anyone into her house

(Dr Khan)

What happened during the assessment?

... Helen had no insight whatsoever –she had no idea what was going on we asked her several times to come into hospital for further assessment – but she refused repeatedly – it was important to get her into hospital

(Dr Khan)

What happened when Helen arrived at hospital?

... she was upset - but there was no alternative to Helen coming into hospital - admission was absolutely necessary - to remain in the community was not an alternative and would not have been appropriate or indeed safe at the time

(Dr Khan)

... she was really unhappy at being in hospital, shouting at everyone, - but she had to come in, she would have posed a major risk to herself if she had remained at home, her health would have quickly deteriorated

(John)

How was Helen while in hospital?

... for a while, there were major concerns over Helen's mental state - she refused to eat, drink or take medication, and lost a lot of weight - several times she expressed her wish to die and asked staff to put poison in her tea - there was no alternative to ECT and I rang next of kin Moira - she raised no objections

(John)

So what was the outcome?

... the medication was having little effect on her mental state - she remained depressed. ECT became the only option and had to be seriously considered - it was in her best interest, no doubt about it

(Dr Khan)

How was Helen at the time of discharge?

... unbelievable – the change was there for all too see and it certainly justified our decision to give her ECT – a short while afterwards she was discharged

(Dr Khan)

... oh, - there was a massive improvement in her mental state – she was a completely different person, so much so arrangements were made with her daughter to return home

(John)

### **Key Themes.**

Helen lived alone (p195) and had not been compliant with her medication - she refused to enter hospital informally (p196) and had behavioural problems on arrival at hospital and during her assessment (p197). Helen was discharged back home following discharge (198)

### **Edward's Experience.**

Edward is seventy years old and had lived with his wife Patricia for over forty years. I had written to Edward asking him to take part in the study. What I did not know at the time was Edward had died from a terminal illness. However, I was able to interview his wife, Patricia alone at her home, Dr Roberts at the Queen Elizabeth hospital and ASW Julie at a psychiatric day centre in Kings Norton. Edward's assessment took place at his home - he had refused all food and medication and was detained under Section 3 of the Mental Health Act (1983) because he was *severely depressed and displaying psychotic features*.

### **Caregiver's Interpretation.**

How was Edward before his assessment?

... the way he was - I'd never seen him like that before, he would not move or talk to me – he just wanted to stay in bed and be left alone. He had recently been diagnosed with cancer – since then he has really been down

What did you do?

... I rang the doctor and told him what was happening - Edward was refusing to eat, take his medication or get out of bed. He got in touch with the hospital – shortly afterwards the social worker rang to say she was coming out

What happened when she arrived?

... she turned up with Dr Roberts and went into the bedroom, I was there – Dr Roberts asked Edward to go into hospital voluntarily, but he wouldn't, he refused.



They said he needed to go into hospital - I had no objection - it was a relief to me, I could not manage any longer – Edward didn't know what was happening

What happened when you arrived at hospital?

... a nurse explained everything to us but Edward didn't understand – he was assessed and moved to a ward - I went with him

How was Edward treated while in hospital?

...the staff were marvellous - I visited every day even though he told me not to, but there was no one else to go, we could not have children, it gave me something to do He was in the right place and the hospital staff - they could not have done anymore

*At this point, Patricia got quite tearful and I suggested a cup of tea. She agreed.*

Do you want to continue?

... oh yes, take no notice of me, I'm always like this, it does me good to talk about it

The ECT - did he agree to have it?

... he would not have been able to - Dr Roberts contacted me and told me the medication was having no effect – he suggested ECT and discussed the benefits

Were you happy to go ahead with it?

... well, you know, what else could I do, I didn't really understand it all but what else could be done – the er, tablets, they weren't working

Did the ECT work?

... Edward was still seriously ill but his depression had lifted and it was much easier to talk to him – so I think it was right to give him the treatment

What happened following Edward's treatment?

... erm, Julie got in touch, oh no – it wasn't Julie, it was Dr Roberts he said Edward's condition had improved but he was still seriously ill – he said it would be best if Edward was moved to another ward so they could care for him, you know his cancer, so I agreed

Is that what happened?

... yes, but Edward died three weeks later - I was at home and received

a phone call from the ward saying Edward was not well - they sent a taxi for me - by the time I got there Edward had died

### **Professional Interpretation.**

How was Edward prior to his assessment?

... over previous months, Edward had lost a lot of weight and complained of stomach pains. His GP referred him to hospital for a scan and Edward was diagnosed with a shadow on the lung – cancer, which was inoperable

(Dr Roberts)

Do you think Edward's illness impacted on him mentally?

... it is highly probable that his physical illness had been a defining factor leading to his mental illness

(Dr Roberts)

What happened when you arrived for the assessment?

... on arrival, Edward was in bed and was very low in mood and lacking energy, he was non-compliant with medication, and totally refused to allow CPN involvement – he did not resist when the ambulance arrived but he refused to enter hospital voluntarily

(Julie)

What happened when you arrived at hospital?

... he believed the police had put a camera behind his eye. When you combine this with his outright refusal to enter hospital informally, there was no option but to formally detain

(Julie)

Did Edward have the capacity at the time to agree to informal admission?

... no, I don't believe he did I wouldn't say so, no – he continually refused to come into hospital, he lacked insight into his condition, so no, he could not have made that decision

(Dr Roberts)

How was Edward while he was in hospital?

... Edward was not unduly distressed about being in hospital, he kept himself to himself and never made any request or attempt to leave the ward

(Dr Roberts)

... Edward had an additional health problem which both he and his wife knew about – he was seriously ill. On top of that the medication was having little

effect. It was decided the best course of action was ECT – there was no option  
(Julie)

Did Edward undergo ECT?

... yes – he did not want to - I fully understood the reasons for Edward`s decision when you consider his emotional distress and lack of clarity, combined with the malignancy, a serious physical illness - I went through all the proper channels, requested a second opinion doctor, who confirmed the requirement for ECT. I also discussed the proposed treatment with Edward`s wife and brother-in-law

(Dr Roberts)

... yes - but it was an absolute necessity if there was to be any improvement in Edward`s mental state and there was

(Julie)

What was the outcome of the ECT?

... three weeks later, Edward was re-graded informal - because of his continuing and deteriorating physical condition, he was unable to return home. I had a long discussion with Patricia and her brother-in-law regarding what would be best for Edward over the following weeks. Eventually it was agreed by all concerned that he should receive palliative care on a general ward, which I arranged

(Dr Roberts)

... Edward was transferred to a general ward within the hospital to receive palliative care – unfortunately he died just a couple of weeks later

(Julie)

### **Key Themes.**

Edward was non – compliant, refused to enter hospital informally and according to professionals lacked any insight into his condition (p200). Good communication was present throughout Edwards experience.

### **Agnes`s Experience.**

Agnes is 68 years old, a widow and lived with her three children in an ex-council house. I interviewed Agnes alone in hospital where she remained informally awaiting discharge. She was quite forgetful and became easily distracted which led to several `silences` during the interview. I spoke with Dr Grimes and ASW John at the Queen Elizabeth hospital. Agnes was detained under a Section 3 of the MHA (1983) because she was expressing signs of “*grandiose delusions, and very irritable*”. Finally, I interviewed Agnes`s eldest daughter Mary at her home.

### **Agnes`s Interpretation.**

How were you before you had your assessment?

... I can't remember very much - my daughter told me I was forgetful and at times I was erm, noisy and shouting which isn't like me, I can't remember really

Do you remember anything about the assessment?

... no, not really - I remember people coming to my home and being in an ambulance, but other than that, well no, I just can't

What about when you arrived at hospital – can you remember that?

... I wish I could but, erm before I came into hospital, it's er, just a blur, I only know what people have told me, and I can't believe it – it really worries me

What about your time on the ward – how was that?

... I was treated very well, the nurses were a big help - and the doctors. I stayed in my room - I don't know why, I just did, some of the other patients were very noisy, so I stayed away from them

Has anyone talked to you about being discharged?

... yes, I told them I wanted to go home, but they said that would not be possible – when I asked why, they said because of the care I needed, I have to go into a nursing home – but I don't want to

How has this impacted on you and your family?

... I often think about the trouble I have caused my daughters, but I couldn't help it. even now, I am not sure of what I did or how long I have been in hospital, I keep trying to remember, but I can't

### **Caregiver`s Interpretation.**

How was your mother prior to her assessment?

... she had been very confused and agitated for several months - things have not been the same since dad died. We expected her to be upset, but she became very aggressive towards all of us, to a point where we were scared to talk to her

What did you do?

... I spoke to my brother and sister and we decided to contact our own GP, Dr Vernon. We had no choice, what else could we do? He came out the following afternoon and mother was verbally aggressive towards him. I couldn't believe it, she was swearing at him, telling him to get out, I was so embarrassed, he'd been our family doctor for years.

... Dr Vernon asked her to go to hospital but she refused and eventually he rang for the police and an ambulance. I spoke with her to try and get her to go voluntarily which she did eventually - but she was shouting all the time and would not sit still.

What happened when you arrived at hospital?

... she wasn't happy – she didn't want to be there and was looking for the door all the time – trying to get out, but there was no way – she was shouting a lot – she didn't understand what was happening

What happened during the assessment?

... she had to see another doctor – she was quiet and couldn't answer any questions - that was it really - they had to keep her in - she was asked to go in voluntarily but she wouldn't - she wanted to go home

How was your mother treated while in hospital?

... it took time for her to settle down – even now she is not back to what she was – at first it was awful, each time we went in, something had happened, she caused lots of problems on the ward which naturally I put down to her not being well, sometimes she was nasty

If you had to – would you contact the hospital again?

... yes, we are happy with the treatment and if necessary I would not hesitate to contact the hospital

Did anyone speak to you about discharge?

... yes - but there was absolutely no way mum could have returned home, she couldn't look after herself and I couldn't do it - she needs 24-hour care

How has this experience impacted on your life?

... the whole family feel we had not done enough to help prior to her assessment and now, because of the level of care required, we have been told they are trying

to arrange for mum to go into a nursing home, which we know is what she needs, we feel so left out, I would like to do more

### **Professional Interpretation.**

What circumstances led to Agnes's assessment?

... Agnes's problems can be traced back to the death of her husband – her family have told us that she became forgetful and at times verbally aggressive

(Dr Grimes)

... her health in general seemed to deteriorate very quickly over the previous twelve months – her daughter told me she was refusing to eat or drink and was irritable a lot of the time and refused any help from mental health services

(John)

How was Agnes when she arrived at the hospital?

... she did not want to be here – no doubt about it and she kept telling everyone she was going home – I wouldn't say she was aggressive – but she was angry

(John)

What happened during the assessment?

... Agnes had no insight and was unaware of her own mental health problems - she was in urgent need of further mental health assessment

(Dr Grimes)

... well Agnes did not believe she had a mental health problem and refused to enter hospital informally - there was no option to detention

(John)

How was Agnes during her stay on the ward?

... she was troublesome, some of the other patients were a bit scared of her. Many a time she lashed out at staff, and often threw things at people on the ward. She threw a cup of tea over another patient for no reason

(Dr Grimes)

Is Agnes being discharged?

... at the moment she is still in hospital – albeit informally, but we are trying to get a place in a nearby nursing home – she needs 24 hour care at the moment, she cannot cook or self medicate, so it will be best all round if we can get a permanent place for her and her family agree

(Dr Grimes)

### **Key Themes.**

According to professionals, Agnes had no insight and refused to enter hospital informally (p204) – she had behavioural problems prior to and during her stay in hospital - at times aggressive (p204)

### **John`s Experience.**

John is 67 years old and lives with his wife Moira in their council owned home. I interviewed John alone on the hospital ward – he was confident and provided responses that were immediate which aided the flow of the interview. I spoke to his wife Moira a week after he had been discharged from hospital at their home with John present. I also spoke to Dr Wright, and ASW Helen at the Queen Elizabeth hospital. John`s initial assessment took place at a police station followed by further assessment at hospital where he was eventually detained under Section 3 of the MHA (1983) because of *a relapse of his chronic schizo-affective disorder, characterised by his elated mood, increased energy levels, flight of ideas and grandiose and paranoid delusions.*

### **John`s Interpretation.**

How were you before your assessment?

... I was fine – but my wife and er, my son said I wasn`t – she told me I hadn`t taken my tablets and that`s why I ended up in hospital, I remember the police – they locked me up, don`t know why, I didn`t do anything wrong

Can you remember your assessment?

... oh yes, it happened at home - my wife was there, Dr Wright, and my son Terry - he came around, I think my wife rang him

Do you remember arriving at hospital?

... not really – I can`t think who was there, I wanted to go home but they wouldn`t let me, there was nothing wrong with me – I didn`t hurt anyone are you going to talk to my wife – she`ll tell you

How was your stay in hospital?

... not good - tablets don`t work for me and I kept telling them I needed ECT - it`s the only thing that works for me - that`s the only complaint I have about the hospital, they did not give me the ECT early enough. If they had, I would have been out long ago – but they didn`t listen

How did you get on with the other people on the ward?

... most were ok but one time I had a bit of a skirmish with one of the staff. He was shouting at one of the ladies on the ward and I intervened and hit him, but he overpowered me, he was a lot younger than me.

Would you contact the hospital again if you needed to?

... if I had to, you know, what else could I do, I er, wasn't happy with all the messing about with the tablets I just wish they would have given me the ECT earlier – but they don't listen

What is happening now – can you go home?

... yes, yes, er – I have been allowed to go home one day a week for the last two weeks so I can't complain about the way they have handled the discharge – I have been told I will be going home next week – will you be coming to talk to my wife?

### **Caregiver's Interpretation.**

How was John before his assessment?

... he wasn't taking his medication, I kept telling him but he kept saying he was - I warned him he would end up in hospital – but he didn't listen

What were the events that led to his assessment?

... he took off one morning - I didn't have a clue where he had gone - I started ringing around friends and family – next thing the police arrived and explained they had received a phone call informing them a man was trying to get into a house in the local area - when they responded, they found John trying to force a front door

What had John been doing?

... he had gone to our son's house, and could not understand why he was not in. Terry was at work, John thought it was Sunday. Anyway, when he got no answer, he went around the back of the house and was trying doors and windows - he thought something was wrong inside the house, next thing the police arrived and took him away.

*John said, "I can't remember any of that, I thought it all happened here".*



What happened next?

... I asked them to bring John home because he needed his medication and he would be ok - they said that was not possible, but asked me to go with them to the police station where John was being held. When we arrived, Dr Wright was there and he said John required further assessment in hospital. He said there was no way he could go home

What happened when you arrived at hospital?

... he was arguing with everyone and swearing – he kept saying he was going home – ‘nobody’s going to stop me’ – he didn’t have a clue what was going on

Did he have a further assessment?

... yes – he kept arguing with everyone, before long Dr Wright came out and I knew – they were going to keep him in – to be honest I was glad because I can’t manage him at home when he’s like that

How was John during his stay in hospital?

... the staff on the ward kept telling me he was always arguing with other patients and staff and sometimes got really aggressive – but I blame them, it was their fault, they kept messing with his medication.

What was the outcome?

... the medication wasn’t working - it was decided he needed ECT – we had been telling them that for weeks - once things have gone too far – that’s it - if he keeps up with the tablets, he’s fine, but once he stops taking them, then that’s it, there’s no way back with the tablets, he’s got to have the er, ECT, you know the er, electric treatment, nothing else works

Did the ECT work?

... yes, we continually told staff he needed ECT - but nobody listened until they realised the medication was not working - but he’s home now, goes back once a month to see Dr Wright and that’s it. He’s fine if he keeps up with the tablets, I keep telling him, I can’t watch him all the time

Were you involved in the discharge process?

... we were both involved in regular discussions with Dr Wright and Helen regarding the discharge package and it worked out well. They let him come home for a couple of trial runs and then he was allowed to come home for good

## **Professional Interpretation.**

What were the circumstances that led to John's assessment?

... the main problem was he was not compliant with his medication, which his wife confirmed, as a result he had become troublesome at home to the point where his wife could not manage

What happened next?

... I rang John's wife and arranged to meet her at the police station – when I got there John was verbally aggressive and had to be restrained on several occasions. He kept trying to leave the police station

(Helen)

What was the outcome?

... John needed further assessment so it was decided with his wife that we should get him to hospital - however John had different ideas and became aggressive - the police had to escort us to hospital

(Helen)

How was John when he arrived at hospital?

... he caused major problems and we needed to keep a close eye on him – he was trying to hit out at people including the police, so it was important to get him assessed and move him onto a ward for his own safety

(Dr Wright)

What happened during the assessment?

... John was er, totally delusional and accusing people, including his wife and family of all sorts of things – he wouldn't stop talking, was quite loud, shouting erm, 'I'm going home (laugh) – and no one is stopping me' but there was no chance of that happening - for one, his wife would not cope and to be honest, it would not have been safe at the time, community support had been tried in the past with limited success, but on this occasion it was totally out of the question

(Dr Wright)

... he had no insight into his condition whatsoever – he was asked repeatedly to come into hospital voluntarily but on each occasion he refused saying 'no way – I'm going home' - (pause) he kept getting up and trying to get out, as time went on things got progressively worse so it was important to get him assessed so we could start treatment.

(Helen)

How was John on the ward?

... he was not the easiest person to get on with – he accused people of all sorts of odd things – the medication was not working and so we changed it which may not of helped – eventually he had ECT

(Dr Wright)

... trouble, honestly he was really troublesome and highly aggressive – you could not talk to him, or even approach him – all the other patients avoided him, he was always accusing someone of trying to do something to him

(Helen)

What was the outcome of the ECT?

... it was the case that once he had been given the course of ECT, the recovery was remarkable, he immediately became a lot more stable - in retrospect, John could have been discharged earlier if we had given the ECT earlier

(Dr Wright)

Has John returned home now?

... well yes, and he should be fine if he keeps up with the prescribed medication - it will certainly reduce his chances of re-admission – the problem that I am aware of is that his wife has a continuing alcohol problem, which may reduce her ability at times to monitor and control John's medication

(Dr Wright)

### **Key Themes.**

John was non-compliant with his medication (p 206, 208) and refused to enter hospital informally (p208). John was aggressive and threatening during his assessment and his time in hospital (p208, 209) He was in denial of his mental illness (p205) but was discharged back home (p209)

### **Alice's Experience.**

Alice is 82 years old and lived in warden controlled accommodation. Her husband Thomas is alive, but was in respite care following a stroke. I spoke with Alice alone in a nursing home following discharge from hospital – she was thoughtful and answered questions without hesitation which aided the flow of the interview. I was unable to speak to her husband, but did interview David, her eldest son at his home in Sparkhill. He had been her main carer. I also interviewed Dr Khan and ASW Alan at the Queen Elizabeth hospital. Alice was assessed in hospital and detained under a Section 3 of the MHA (1983) to ensure her *mental health was appropriately assessed and treated to avoid any further deterioration.*

### **Alice's Interpretation.**

How were you before your assessment?

... I haven't been well for a while now, my husband is not well either – he's in hospital somewhere, not sure where. I know Dr Khan came to see me before I came in hospital – I can't remember really - I'm very forgetful

What happened during your assessment?

... I think I was at home and er, Dr Khan came – he kept asking me to go into hospital, oh and there was erm, someone else there, can't think now, but I didn't want to come into hospital

What happened when you arrived at hospital?

... Dr Khan was there – but there were some other people, I think they were doctors and a nurse as well – they were all trying to get me to go into hospital – but I didn't want to – I can't remember much

How were you treated while you were in hospital?

... fine -most of the doctors were ok - but I should not have been in hospital - I have two sons and a daughter and they could have looked after me - people were saying things about me that weren't true, they made me out to be crackers

What sort of things?

... people were saying I had hit my husband, and I never have – and I did not attack my daughter-in-law – but they all said I did

Did anyone talk to you about leaving hospital?

... yes, the nurse spoke to me and then one of the doctors – but they said I could not go home, they wanted me to go into a, er, you know a care home – but I did not want to, I can look after myself

What was the outcome?

... I ended up in here, I don't want to stay here, I want to go back to my own flat – I'm happy there, my friends are there – I spoke to my son but he thinks for the time being I am best in here

Would you contact the hospital again if you needed to?

... no, no, not at all – I didn't want to go in last time but they made me – you get no say, they just do what they want – I just want to be left alone, I'm happy in my flat – wish they would leave me alone

### **Caregiver's Interpretation.**

How was your mother prior to her assessment?

... we have been aware of problems for about two years – there has been a gradual decline in her mental health, but it has got worse over the last three or four months - one day, I received a call from the warden at mum's flats saying there had been problems – so I went over.

What sort of problems?

... there's been a few things - she had been buying excessive amounts of food, for example there were lots of jars of coffee in the kitchen. I've been told she had been opening her purse when in town and recently called the police on 999 to report minor incidents around her home. The smoke alarm went off because she left a meal in the oven - she called the fire brigade out

... she told me she had seen dead relatives and I have heard her talking to them at her home - she got very angry one night in her flat because I would not tell her where dad was and she did not attack me, but hit my wife

What happened when you got to your mum's flat?

... Alan explained the situation to me - she was sitting in the dark, there was no heating on and it was really cold that day - she said she had not eaten for days - I talked mum into going to the hospital.

How was your mother when you arrived at hospital?

... we were taken into a room and told what was going to happen – we were treated well, but mum was not happy, she was asking for dad all the time – it was a difficult situation but I had no complaints

Were you happy with the assessment?

... well yes, I suppose so – I didn't know what to expect to be honest- it didn't take too long – the questions they were asking mum couldn't answer – she just kept going on about dad – she was asked to go into hospital voluntarily but said no – I was told she would be kept in for her own safety

How was your mother while in hospital?

... things were not good at first – I kept getting calls saying she was not taking her tablets – the staff were good - they told her it was important to take them – eventually she settled down – I told her she would be in hospital longer if she never took her medication

Did she listen?

... well she listened but, er she still wouldn't take the tablets, I don't think she really understood the consequences – but I know Dr Khan also spoke to her and things changed – she started to take the medication, she settled down and behaved herself - not long after – she was being considered for discharge

Were you involved in discussions relating to discharge?

... several times - it was explained to me the possible problems of letting mum return to her flat. It was agreed, except by mum, it would be best if a place was found in a nursing home. - she could not take care of herself - she will end up back in hospital – we could not give her the care she needed, it would have been nice for to return home, but I am happy with the way things have turned out

### **Professional Interpretation.**

What were Alice's circumstances prior to her assessment?

... Alice has a history of cognitive decline with a day-to-day fluctuation – she has lived alone for over 12 months - her husband, who is a wheelchair user, is still alive but he's in a nursing home following a stroke - she had become aggressive and there were strong suspicions Alice had been abusing him  
(Dr Khan)

... There had been suspicions for quite a long time that Alice had been hitting her husband. She denied it, but when I visited them at their home, Thomas would gesture that Alice had been hitting him, and from what I have heard, had in fact tried to strangle him  
(Alan)

What happened next?

... I received a phone call from the warden who was concerned about Alice. When I arrived, Alice was sitting alone - it was very cold and the lights were turned off. I asked Alice about it and she said it was light enough and she had only just turned the heating off. I doubted this – I also asked if she had eaten and she answered yes - again I had my doubts.  
(Alan)

How was Alice when she arrived at hospital?

... she was agitated and couldn't answer questions but kept going on about her husband wanting to know where he was – I told her he was in a nursing home  
(Alan)

How was Alice during the assessment?

... she was pre-occupied with the whereabouts of her husband - she kept denying she had hit him, saying they had been together since she was 17 – she had no insight and had become a danger to herself and others – she refused to enter hospital informally so we had no option but to detain her  
(Dr Khan)

How was Alice during her time in hospital?

...she was aggressive to begin with and not complying with her medication - staff reported Alice spitting her medication out, refusing to eat or drink and her son was contacted and informed of his mother's behaviour  
(Dr Khan)

... Alice settled down when she began to comply with the medication - she became a lot quieter around the ward, was eating her meals, sleeping well and in general was getting better by the day  
(Alan)

How was Alice at the time of discharge?

... there was a marked improvement in her mental state - we had several discussions with Alice and her family before she was discharged – there was no way she could return home, which everyone agreed with - as far as I know she has settled in a er, nursing home now  
(Dr Khan)

... she was much better, but there was a fear she could not look after herself - the feeling was that Alice may forget to take her medication and could end up back in hospital especially following the problems we had on the ward, you know, she refused to take her medication  
(Alan)

### **Key Themes.**

Alice lived alone prior to her assessment (p209) and according to professionals, lacked insight into her mental illness (p213) and refused to eat or take medication (p212) She had behavioural problems prior to and on arrival at hospital (p213)

### **Anne`s Experience.**

Anne is a 72 years old widow and lives alone in warden accommodation. She has two daughters, one living in Ireland and another who had recently suffered a severe stroke and was in hospital. I spoke to Anne alone in her home following discharge from hospital. She was visibly upset and at times angry because of what had happened to her which affected the flow of the interview. Under the present circumstances, it was not possible to talk to either daughter, but I did interview her brother Robert who lived locally in Edgbaston. I also interviewed Dr Edward Wright at the Queen Elizabeth hospital and ASW Alison at a local respite centre in Harborne. Anne was detained under a Section 3 of the MHA (1983) because she had a “*known bipolar affective disorder with psychotic symptoms*”.

### **Anne`s Interpretation.**

How were you before your assessment?

... I remember being a lot more irritable and being very nasty to others but I put it down to my arthritis – I get pains in my legs, my main concern was for my daughter – she suffered a severe stroke and was in hospital

Do you remember your assessment?

... I remember some of it – my brother came over with someone from the hospital I think it was a nurse – the warden rang them – he`s a right busy-body, my brother asked me to go to hospital, it would be best he said – I didn`t want to, but in the end I did and they kept me in

What happened when you arrived at hospital?

... oh, I was fed up, I didn`t want to be there – wish they would have left me alone – a doctor was talking to me and someone else, I couldn`t follow what was going on – it was all confusing to me

How was your stay in hospital?

... awful, I shouldn`t have been in there - no, I did not enjoy it, but you get no say, they asked me did I want to go in and I said no – I just gave up in the end – they kept saying I had to calm down, I was being er, aggressive with people, but I don`t remember that, no

Did anyone talk to you about being discharged?

... I remember being told about going back home - I was so happy, they said someone would come in and see me to make sure things were ok – I am not bothered if they come or not – I hope they stay away



What impact has this experience had on you?

... I tend not to think about it too much - it's become part of my life and I just have to accept it, what else can I do?

Would you contact the hospital again if you needed to?

... no, what for – they'll only keep me in hospital again and I don't want that - no, I'll just look after myself, I don't need them - they can all stay away

### **Robert's Interpretation.**

How was your mother before her assessment?

... she's had mental health problems for over 50 years - this is the third time in the last two years she has been detained - on this occasion there were concerns regarding her behaviour – she was not taking her tablets

What happened at the assessment?

... it was all straight-forward – nobody spoke to me really but it was a foregone conclusion she was going to be kept in –she was forgetful but she was asked to go in voluntarily - she kept saying no

How was Anne treated during her time in hospital?

... she was agitated at first but was treated well - nothing was too much trouble – she just wants to be left alone but sometimes she is so down she needs help

Did Anne get on with other people on the ward?

... no, not really – she didn't get on with anyone at first, but I think it was to do with her medication – it took her a while to settle down, but after time she was fine – well she's back home now

Were you involved in discussions about discharge?

... yes, I got several calls – it was handled really well – I've got no complaints, before she was discharged she had two weekends back home which went very well

How has Anne's detention impacted on you?

... she's had problems for that long now, it does not bother me anymore, you sort of expect it to happen now and again and when it does, you have to deal with it.

## **Professional Interpretation.**

What were the circumstances prior to Anne's assessment?

... she had not been complying with medication and became elated at times with reduced sleep patterns - this formed part of a clear relapse pattern for her

(Dr Wright)

... she had been unwell for about two weeks prior to the assessment - she was continually agitated, resulting in very aggressive verbal outbursts

(Alison)

What happened during the assessment?

... Anne had the capacity to enter hospital informally but she continually refused – she would not accept anything was wrong – she really was agitated and talking non stop – in the end there was no alternative, because of her non-compliance, she needed time in hospital to assess her level of functioning and well-being

(Dr Wright)

How was Anne when she arrived at hospital?

... she was very noisy and aggressive, but er, although she had some insight into her condition – she refused to come into hospital voluntarily

(Alison)

How was Anne while she was in hospital?

... at first she continued to be noisy while on the ward so much so, because of her behaviour and the upset she was causing, the lady she shared with was moved to another ward - eventually she became fully compliant with her medication and no longer complained about cramps in her legs

(Dr Wright)

What happened around the time of discharge?

... Anne had become really well behaved on the ward and was fully compliant with her medication - a meeting was arranged to discuss discharge - a Community Rehabilitation Team was involved as part of the package and she will be reviewed monthly as an outpatient

(Dr Wright)

... once Anne became compliant with her medication, she settled down well – she was well behaved and got on well with staff and other patients - so in full agreement with Anne and her brother, who were included in the meetings, a discharge package was put together and er, as you may know, she has returned home now

(Alison)

### **Key Themes.**

Anne lived alone and had been non compliant with her medication (p214). She had ongoing behavioural problems prior to and during her stay in hospital (p 216). She also refused to enter hospital informally (p 216). Anne was discharged back home(216)

### **Joseph`s Experience.**

Joseph is 73 years old, divorced and lived alone in rented accommodation. He had lost touch with his only brother over a dispute many years ago. I interviewed Joseph alone on the hospital ward – he was happy to talk but at times became forgetful which disrupted the flow of the interview. I contacted Joseph`s stepdaughter Pamela, and she agreed to be interviewed at the University of Birmingham. I spoke to Dr Khan and ASW Kimberley at the Queen Elizabeth hospital. Joseph was detained under a Section 3 of the MHA (1983) because of “*severe cognitive impairment with psychotic delusions of persecution*”.

### **Joseph`s Interpretation.**

How were you feeling in the time leading up to your assessment?

... I can`t remember too much – one of the staff said I had threatened one of my neighbours, I don`t know who, or why, but that`s what they said, so I don`t know – I was told the police brought me in

What happened when you arrived at hospital?

... the police were there - there was all sorts of people there but I didn`t know any of them – I`ve been told I was trying to leave all the time, but I can`t remember doing that – it`s only what others say

Can you remember your assessment?

... no, not really – just what people are telling me, my niece has been in but she did not say much – not sure if she knows what happened – I`m so fed up, they said I can`t go home

How have you been treated in hospital?

... I`m not sure how long I have been in – the last few weeks have been ok - the staff have been fine, – I can`t remember any problems, there may have been but I don`t know for sure

Would you contact the hospital if necessary?

... no way, I wouldn't come back in here - I told them I did not want to come into hospital, but they still kept me in

Were you involved in discussions at the time of discharge?

... yes – they told me it would be best if I was to go into residential care - I said no at the meeting – I wanted to go back home but they er, didn't giving me a choice - they were telling me what was happening, that's the way it works in here

How has this whole experience impacted on you?

... it's ruined my life - people do not trust me, they stay away, I've got no friends and had no contact with family members in years - I feel so let down and alone - if someone was there for me, you know, before I take ill, then I might not end up in hospital. I know I have a problem with medication, but that's because I forget to take it, that's all, I don't do it on purpose

### **Pamela's Interpretation.**

Were you aware of Joseph's circumstances before his assessment?

... I have not seen him for two years - he's fallen out with everyone - he's so difficult to be with and frightening - one of his neighbours told me he came out of the house and started shouting about someone stealing all his money, when they tried to talk to him he started screaming - he was threatening people and they thought he was going to hurt someone, so they called the police

So what was the outcome?

... the police knew him from previous incidents and decided to call for an ambulance – he was shouting 'I did not attack my neighbour with a hammer' – his neighbour said when the ambulance arrived, he got in without any fuss

What happened when he arrived in hospital?

... I er, wasn't there and I'm glad – even if I had known about it I wouldn't have gone – the staff said he was fighting and causing trouble - typical

Do you know what happened during the assessment?

... Kimberley said – I think she's a social worker – she said he wouldn't stay in and was trying to leave all the time – he was arguing with staff

How was he treated in hospital?

... the staff are all nice, he's been treated fine - I did go to see him, once, (stressed) that was enough – he said he was not happy – he kept saying he had done nothing wrong, but from what I have been told I'm not surprised he's been kept in – he's just not safe on his own

How did he get on with other people on the ward?

... I spoke with a nurse who told me he had been troublesome on the ward - he was not eating or drinking and refused to take his medication – he was also aggressive with everyone and was constantly trying to leave the ward - one day he was caught trying to climb over the garden fence

Were you kept informed when Joseph was being discharged?

... no – but they knew I wasn't interested – I got one phone call telling me he was going into a nursing home and that was it – as far as I'm concerned that's it now – if I did go over again, it will be with my boyfriend – I wouldn't go over and be on my own with him – he's not safe

### **Professional Interpretation.**

How was Joseph prior to his assessment?

... Joseph was totally deluded believing his neighbours were threatening him and his money was being stolen - reports from police indicated that Joseph was very aggressive towards both them and his neighbours

(Dr Khan)

... Joseph had a dispute with neighbours and the police were called. He said they had threatened to kill him, and had smashed his front door in - he said his ex wife had taken all his money - £4 million

(Kimberley)

What was the outcome?

... his neighbours were frightened of what he was going to do next so one of them called the police – they knew Joseph from previous incidents and decided to bring him into hospital

(Kimberley)

What happened when Joseph arrived at hospital?

... he arrived with the police, I was called and attended with one of the social workers – he was trying to leave all the time - his violent

behaviour continued from the time he arrived and throughout the assessment – he was difficult to manage

(Dr Khan)

How was Joseph during the assessment?

... he did not have any insight and continued to be aggressive -he was certainly a risk to other people - Joseph had a mental illness characterised by paranoid delusions and memory difficulties which required him to enter hospital for treatment - he refused to enter hospital informally

(Dr Khan)

... Joseph was spontaneous during the assessment but was unable to remember his ex wife's name, or who his next of kin was - he repeatedly claimed he was being robbed by his family of 11 brothers and five sisters – this was completely untrue

(Kimberley)

How was Joseph while he was in hospital?

... when he first entered hospital he was really difficult – his delusions continued - he thought he was being poisoned and refused to take any medication – after a while he settled on the ward and his condition became more manageable

(Dr Khan)

... at first he refused to take any medication, would not eat and was continually arguing with staff and other patients – but I've got to say that eventually he came around and started to comply with his medication and the improvement was almost immediate

(Kimberley)

Joseph is awaiting discharge – why can't he return home?

... well there is a problem - Joseph has been included in discussions around his discharge and we have explained to him that admission to a care home would be appropriate at this time - he did object but there is ongoing concern relating to his repeated non-compliance with medication

(Dr Khan)

... Joseph does have a problem complying with his medication – but I do honestly think he forgets to take it - so there is a serious chance of relapse. I don't think it is something Joseph does consciously, but it is a problem and something we had to take into account when we were putting the discharge package together

(Kimberley)

### **Key Themes.**

Joseph had behavioural problems prior to and during his assessment (p 218, 219) and was non - compliant with his medication (p 220) Professionals stated he did not have any insight into his mental illness and refused to enter hospital informally (p 220)

## ***Chapter 7.***

### **An Interpretative Phenomenological Analysis of an Older Person's Experience of the Use of the Mental Health Act (MHA) (1983)**

#### **Introduction.**

Within this research project, case studies have allowed the exploration of a key social process; the use of the MHA (1983) with older people. Although there are a variety of specific aims and research questions, the general objective is to develop a fuller understanding of the phenomenon being explored in its real-life context. Hence, this chapter will systematically identify commonalities and differences as expressed by all participants within the case studies presented in the previous chapter and analyse these in relation to relevant literature.

Initially, I will discuss the barriers to an older person becoming a mental health service user and then, in line with an IPA approach, I will present a layered analysis of the phenomenon at a descriptive phenomenological level while conveying an empathic understanding of the experience of the older person's experience, and also, a probing analysis based on the deeper interpretative work of the researcher (Eatough and Smith, 2008) The focus remains the participant's attempt to make sense of their experience as the analysis progresses from the particular to the shared and from the descriptive to the interpretative (Smith, Flowers and Larkin, 2009)

Examples from Narrative	Emergent Themes	Exploratory Comments.
<p>Alison - `no one told you anything unless you asked` (p:198)</p> <p>Charlotte `became very angry and aggressive` (p:187) Harry became `threatening` (p:197)</p> <p>Michael - `I live alone – I don't need anybody` (p:204)</p> <p>George - `they have too much power` (p:217)</p> <p>Alison – `no one asked what we thought` (p:198)</p>	<p><b>Barriers to receiving services</b></p> <ul style="list-style-type: none"> <li>• Caregiver/family lack of knowledge</li> <li>• Ageism</li> </ul> <p><b>Emotions, Behaviour</b></p> <ul style="list-style-type: none"> <li>• aggression,</li> <li>• denial,</li> <li>• loss of control</li> </ul> <p><b>Social factors</b></p> <ul style="list-style-type: none"> <li>• Living alone</li> <li>• Loneliness</li> <li>• Good/poor family relationships</li> </ul> <p><b>Power issues</b></p> <ul style="list-style-type: none"> <li>• powerlessness</li> <li>• exclusion at time of assessment and discharge</li> <li>• communication</li> <li>• knowledge</li> </ul> <p><b>Medicalisation</b></p> <ul style="list-style-type: none"> <li>• Exclusion from care discussions</li> <li>• social inequality,</li> <li>• non-compliance</li> </ul>	<p>If family/caregivers had the knowledge to help recognise the signs of distress at an early stage, compulsory detention may be avoided</p> <p>Aggression may be an antecedent of mental illness in older people</p> <p>Good quality relationships can promote compliance and reduce disengagement from services</p> <p>Exclusion can lead to non-compliance and disengagement from services.</p> <p>The possible benefits of medicalisation may not be fully understood because of the older person's/caregiver's exclusion.</p>

**Fig 7.1 – Themes/Sub-Themes raised by participants during the narrative interviews.**

The analysis will be structured around emergent **themes** and sub-themes (Fig 7:1) illustrated above including the conflicting perspectives expressed by the different participants, including the different emotions experienced by the older person



around the time of assessment; social and relationship issues; evidence of power inequalities within and between the narratives and finally the iatrogenic effects of mental health services, for example, how the older person's experience of the mental health system, may have impacted on their experience. The themes presented could generate many exploratory comments therefore, those stated are presented as hypotheses to be explored and have been generated from the narrative study providing a basic framework for analysis. An older person's experience of mental distress may start before assessment has taken place hence, this chapter will first provide a discussion relating to the possible barriers to becoming a mental health service user.

### **Barriers to becoming a Mental Health Service User.**

Coppock and Dunn (2010) suggest that often, what triggers contact with mental health services initially is a third party's observation and/or concern that a person's mood or behaviour has changed as was observed within the qualitative study. Several family members/caregivers formed lay judgements related to the older person's behaviour before any formal assessment took place and so contacted mental health services. Harry's aggression was identified by his daughters – he became threatening to all who knew him. Harry's case does require further consideration. Alison said Harry thought his wife 'was seeing someone else'. There was no evidence to prove this claim or otherwise but if it was true, Harry's aggression may be viewed by some as a natural reaction. Hence, does a change in behaviour automatically point to a person being mentally ill or are they simply

mis-behaving? As Barnes and Maple (1992) stated, with unprecedented numbers of older people in western societies, we may be diagnosing some with a condition which is simply no more than a set of behaviours viewed otherwise as problematic aspects of ageing.

Michael became `verbally and physically abusive` and according to professionals, John had `become troublesome at home` while Joseph was `aggressive towards both police and neighbours`. All older people mentioned above were detained in hospital following assessment so possibly, lack of information and knowledge relating to antecedents to mental distress may be a key issue for caregivers. As Alison said, `no one told you anything unless you asked`. If caregivers were made aware of the behavioural changes that sometimes accompany distress, they could notify services at an early stage and the chances of avoiding compulsory detention may be improved. Consequently, lack of knowledge may unintentionally become a barrier to receiving appropriate services at an appropriate time. Gilley *et al* (1997) confirmed that symptoms prior to assessment can often be associated with aggressive or disruptive behaviour. For example, Harry`s family may have thought his behaviour was a direct result of believing his wife was `seeing a third party`.

According to Harry`s daughters the previous 12 months had been traumatic` - ASW James said `Michael had been troublesome for some time` - Josephine`s son said `she had not been well, not well for a long time, we recognised the signs – nobody listened`. ASW Ned said George `over the previous months had been displaying

strange behaviour`. According to professionals `Katherine had been having problems for well over two years` Moira said her mum `had been down for some time`. From the relatively small sample within this study, evidence is described above of examples where signs of mental distress had been evident for long periods but intervention was left until crisis point had been reached and admission to hospital took place. Some professionals appear to adopt a `wait and see` policy, whereby everyone waits for something to happen which possibly reflects the dominant position held by professionals. The picture that emerges from this study is one of some caregivers needing a quicker response from professionals, which because of delays, had implications for the older person and their families by delaying assessment.

#### Improve Knowledge – Early Intervention - Avoid Compulsion?

According to professionals, Harry, Charlotte and Michael were in denial of their mental disorder all stating `there was nothing wrong` and so were not accepting of any diagnosis and refused to enter hospital voluntarily. It may take time for an older person to come to terms with being diagnosed as having a mental disorder and so they may become confused and scared about what it means for them, their families and for their future - what is going to happen and whether they are going to get better. Harry did not have a mental health history although Charlotte and Michael had suffered mental distress/illness for more than thirty years resulting in detention on several occasions. All three were aggressive during their assessments and on arrival at hospital. The main difference was at the time of discharge from hospital.

Harry had close family at home and was allowed to return home where he was admitted from. Charlotte and Michael however, were not allowed to return home mainly as a result of living alone and not having family who were willing or able to care for them. As Lefley (1998) concluded some family members have not planned for this role and simply do not want to do it.

For whatever reason, several families did not contact services until a crisis point had been reached and compulsion was unavoidable. Rita's son Brian said, 'I didn't realise the seriousness – but I do now'. What was noticeable during the interviews was that formal diagnosis was never mentioned by any older person or their families/caregivers. Possibly because of their lack of knowledge, diagnosis did not seem particularly meaningful or important to them. When I asked questions about Harry, Charlotte and Michael for example, their respective families focused on their unusual behaviour as described above. In total contrast, professionals said Charlotte had 'psychotic symptoms, hallucinations and delusional beliefs' while Michael was described as having 'hypomania with pressure of speech and flight of ideas' which their families may have been told about at some point – but if so, they never mentioned it during interviews because possibly diagnosis was simply a name – a label. Lay people do not think or speak using medical terminology which is not surprising but it may implicitly tell us something about their understanding of what exactly is wrong with the older person. They may not understand the diagnosis and so not question it partly through ignorance and partly through lack of knowledge.

Education may be the key here to help obtain early intervention/assessment which may avoid the need for admission to hospital. Although the study was not specifically focused on older people but still highly relevant, Askey *et al* (2009) highlighted the importance of providing carers with information on mental distress, and also that it would be useful for carers to receive training to provide them with strategies in dealing with and understanding more about early warning signs and relapse prevention. Harry's daughters were concerned about his irrational and unusual behaviour stating 'the previous twelve months had been traumatic' but did not associate it with any form of mental distress. According to professionals 'Michael had been troublesome for a long time' - Valerie 'had been depressed for some time' and Agnes had 'deteriorated very quickly over the previous twelve months'. If compulsory detention is to be avoided then early intervention will be absolutely necessary but if family and caregivers are unaware of the signs they witness on a day to day basis then compulsion may be unavoidable. The economic case for early intervention services is gaining strength. McCrone *et al* (2010) confirm there have been several published economic evaluations from Sweden and Australia showing early intervention teams are cost-effective because of the reduction in in-patient stay.

Families may find it difficult to talk about mental illness because of the associated stigma which in turn can deter them and become a barrier to seeking professional help. Thornicroft (2008) offers a highly relevant theoretical perspective suggesting a relation between stigma and knowledge. Stigma is a type of overarching term,

but very imprecise, and the world has not made significant strides so far in terms of reducing its impact within mental health circles. Thornicroft (2008) states it may actually be more helpful to see stigma containing specific challenges particularly the problem of knowledge, namely most of what we all think and know about mental illness is actually very limited and so much of the knowledge people have is actually wrong, and becomes a mixture of ignorance and misinformation which could easily apply to several families within this study – their lack of knowledge led to delays in contacting services in time to avoid compulsory admission to hospital. This conveys an acceptance of the medical regime - that all would be well if only people were better educated, sought help earlier and entered the mental health system and received treatment earlier. Compare this with the narratives of several mental health service users within this study, (Harry, Michael, and John) who say their biggest problems arose from mental health treatment itself, rather than the illness. Harry and Michael described their medication as `poison` while John complained constantly, along with his wife of receiving the wrong treatment. Harry's daughters may have thought his aggressive behaviour was connected to his misplaced beliefs never thinking it may be the result of a form of mental distress. They simply lacked the knowledge to make the connection which is why they continually requested information from doctors and ward staff. Additionally, Harry's extended family and friends may have stayed away possibly because of their limited knowledge around mental illness – in their mind Harry may have been a danger to them. It is not that the people are malevolent; it is that the information

they have is extremely scarce, often partial and almost entirely negative. According to Thornicroft (2008) it is remarkably common for close friends and often family members to distance themselves and often lose all contact with previous family once a mental illness has been diagnosed – possibly as a direct result of the attached stigma, misinformation and lack of appropriate knowledge which has helped demonise mental illness. Sartorius (2000) refers to iatrogenic stigma, that is, stigma caused or perpetuated by mental health professionals or systems, stating that certain actions on the part of the professionals themselves perpetuate stigma, for example, diagnosing a person with mental illness, which in turn leads to labelling and the often side effects of medications. Stigma involves problems with knowledge, attitudes and behaviour and arguably, professionals have a duty to reduce it at the older person, caregiver, family, and societal levels to help reduce its association with potential ‘barriers to mental health services’.

#### Ageism as a Barrier to Appropriate Mental Health Services.

Access to mental health services is not always a straight forward process for older people. Just 13% of older people received an assessment at home and none received treatment of any kind until they had received an assessment in hospital after which they were compulsorily detained. Dr Wright said they ‘needed to get Charlotte to hospital for further assessment’ and according to Alison, Harry was ‘put in an ambulance and taken to hospital for further assessment’ while Charlotte stated the nurse said she was ‘taking me for a drive in her car but before long we were at the hospital’. Valerie’s husband confirmed her assessment took place ‘at

the hospital`. The older people mentioned above were showing varying levels of aggression, anger, and anxiety which may have led to professionals making a decision to transfer the older person to a place of safety, as mentioned in John's case – for example a hospital for further assessment. Alternatively, the older person may have been denied an assessment at home simply based on their age. Age discrimination has been recognised by the Royal College of Psychiatrists (2009) who stated if a person under 65 has a mental health crisis, they would receive an assessment and treatment at home from a 24-hour crisis team – people over 65 would not. Age, in itself, is unsatisfactory as the single criterion for access to services in later life. No person should be required to attend older people's mental health services by virtue of their age alone, nor, for that reason, should they be prevented from attending alternative services that better meet their need – for example, intermediate services provided at home. Although the evidence for supporting older people at home with mental health problems is not as strong as it is for working-age adults, Joy (2006) reviewed crisis intervention studies and found that family satisfaction was higher with home care than inpatient care. This Cochrane review showed that crisis intervention reduced hospital admission or time spent in hospital, repeat admissions and disengagement with services.

### **Behaviour and Emotions at the Time of Assessment.**

Aggression, denial and to a certain extent, non-compliance with medication may be considered `challenging` behaviour, but may be viewed as symptomatic of other things. The whole concept requires careful consideration. According to ASW



James, Michael `had been troublesome for some time and we had been getting regular reports of him being aggressive to the carers, he refused all offers of help`. Similarly, prior to John's assessment, ASW Helen said he was `verbally aggressive and had to be restrained on several occasions`. Joseph's niece Kimberley said he was `aggressive, certainly a risk to other people and refused to enter hospital informally`. Charlotte, Valerie, Agnes, Anne and Joseph were all described as aggressive when they arrived at hospital for further assessment. According to Dr Wright, Charlotte `became very angry and aggressive` while Dr Khan described Valerie as `not very accepting of her situation and at one point, became very aggressive towards her husband`. It is worthwhile, therefore, to be aware of the potential for aggressive behaviour which might emanate as a result of professional intervention because they are often seen as responsible for decisions involving admission to hospital. Levels of anxiety are sometimes palpable at the time of assessment - a time when various emotions were expressed.

Thirty-three per cent of older people within this study were described as `aggressive` while a further 40% were angry/shouting and 33% continually attempted to leave the hospital - which may be a manifestation of their mental distress. According to the Royal College of Psychiatrists (2009) it is important to be aware of the background to aggressive behaviour as it may be directly linked to a previous experience during their life course. The hospital environment may, for some older people, be at the root of the problem because it can be extremely stressful, especially for those who depend upon familiar surroundings for their

overall peace of mind. All older people within this study were taken to hospital for further assessment/treatment. Some may have given up their personal belongings, marks of their identity, in a strange place without familiar and usual routines. Several had been left alone awaiting their assessment without any explanation of what was going to happen which would undoubtedly raise anxiety levels. Harry said `I was just left- no one spoke to me, I just wanted to go home`. Michael said `no one spoke to me, I wasn't told anything, they tell you nothing just keep you in the dark`. Anne said `a doctor was talking to me and someone else – I couldn't follow what was going on, it was all confusing to me`. For most of the time, there may be no one to talk to and so they feel frightened at what is going to happen to them and frustrated at being unable to understand others or make themselves understood – they are surrounded by `disorder`.

There are several factors facing older people that may predispose them to aggressive behaviour. According to Norman and Redfern (1997) common factors include;

- Frustration associated with failing physical abilities; (Michael, Edward, Anne)
- Problems of perception that cause some older people to believe their personal space is being invaded by others, especially unknown caregivers who they may fail to recognise. (Harry, Charlotte, Michael, Agnes)
- Memory difficulties that may lead older people to believe someone has stolen or hidden their belongings. (Joseph)
- Poor care practices which lead older people to be neglected or ignored – thus aggression may become their only means of self expression. (Harry, Michael)

Norman and Redfern (1997) confirmed that aggression, disruptive behaviour or expressions of anger for example shouting are significant and exacting problems in

the care and treatment of older people both in the community (prior to assessment) and in care settings (on arrival at hospital/during assessment) Aggression is one of the most frequently used reasons for referral to psycho geriatric services and recognised as dominant and pervasive problems for caregivers, and are possibly the main reason caregivers seek help.

Fifty per cent of older people within the qualitative study had no recollection of arriving in hospital while 26% did not understand what was being asked of them which relates to Kendell and Zealley (1993) discussion in chapter one related to cognition and memory. According to professionals, 86% of older people within this study lacked capacity/insight or had some form of cognitive impairment which may explain why 55% of older people within this study, when asked, could not remember their assessment. Charlotte said `assessment – what assessment, I don't think I had one`. Michael stated `I don't think I had one – I don't remember, they're a waste of time, they just do what they want, you have no say`. When I asked Katherine if she remembered her assessment she commented `not a lot – I kept looking for my son, I was scared, I didn't know what was going to happen` while Rita said `no, not really, I don't remember`. Helen said `I can't remember the exact reasons but I haven't been well for a while`. Put in context, this was a time when the older person, suffering from mental distress was awaiting appropriate treatment, which may be one particular reason why, at this critical time, some could not recall their experience.

### Impact of Older Person's Behaviour on Families/Caregivers.

One implication of our ageing population is an increased focus on supporting family caregivers who are providing care for dependent elderly relatives. However, more and more caregivers are themselves older persons and they not only have to deal with their caring responsibilities, but they also have to deal with their own increased risk of age associated health problems. Seventy-three per cent of the older people within this study were being cared for by an older adult, either their spouse or an older child. According to Ross *et al* (2008) most unpaid care for older people is provided by a spouse or older adult. Several caregivers spoke about the problem behaviours exhibited by the older person which seems to represent the greatest challenge and clearly affected their sense of well-being – this was the time when they decided they had no option but to contact the professionals. The most common disturbing behaviour described by caregivers was physical and verbal aggression and threats – an example of the subjective burden some caregivers needed to withstand. These findings support similar findings reported by Ayrres and Woodtli (2001) and Vaddadi *et al* (2002) that ageing caregivers are at risk of verbal and physical abuse. Many caregivers became upset as they told of their experiences.

Michael was described as `impatient and angry` by his sister who added `we can't take care of him – he`s really hard work`. Brian said Rita was `angry and aggressive towards everyone - I was in a state of shock, everything happened so fast, life can change so quickly`. Mary said Agnes had `not been the same since

dad died – she became very aggressive towards all of us to a point we were scared to talk to her`. Pamela said Joseph was `so difficult to be with and frightening – I would not go over to see him on my own, he`s not safe`. The respective behaviour was confirmed by professionals during interviews. The findings clearly suggest that these experiences may have impacted heavily upon some caregivers. Harry's wife died and had left his family in turmoil; Charlotte's family was left completely broken; Agnes's family felt they could have done more to help avoid their mother going into hospital while John's wife had an alcohol problem. While several caregivers made comments about having to live with or deal with the verbal aggression exhibited by the older person some seemed almost 'immune' to this type of behaviour and had learned over time to ignore it as best they could. Anne's son Robert stated `it does not bother me any more, you sort of expect it and when it does you have to deal with it`.

According to Vaddadi *et al* (2002) some older caregivers live in environments where they have to contend with the unpredictable and often aggressive nature of severe mental illness. Many caregivers within this study were caught in an unpredictable cycle of caregiving which may oscillate from days of relative normality to days of complete upheaval where the caregiver has to cope with behavioural problems such as aggression, violence, threats and manipulation, as well as accommodate their own stress-related problems. From a phenomenological perspective, family members may have trouble understanding any difficulties the older person is having, finding it difficult to deal with strange thinking and bizarre

and unpredictable behaviour. Families of people with mental disorder are confused, frightened and exhausted. According to Ross (2008) even when the older person is stabilized on medication constant stress and concern can create serious family problems, for example who, if anyone, undertakes the caregiving role. Family life can be unsettled and unpredictable because the needs of the older person become paramount while the needs of the caregivers and the usual problems of everyday life are largely overshadowed.

Sayce (2000) suggests that despite their obvious benefits, good quality relationships between professionals and caregivers have been slow to develop in the area of mental health for a number of reasons. Firstly, there would be a requirement for medical staff to give up outmoded ideologies about family pathology and develop sensitivity to caregivers' needs. Secondly, the sharing of power between staff and caregivers and the ability on the part of professionals to listen and sometimes acknowledge their ignorance has often been absent. Mental health professionals, especially those working within the medical model, are used to being in a position of power and being considered as experts. However, Faulkner and Thomas (2002:3) argue that a "marriage of two types of expertise is the essential ingredient for the best mental health care: expertise by experience and expertise by profession". From the point of view of caregivers, it is important to ensure that such relationships do not reinforce the powerlessness they often experience. The older person and caregivers' dependence and

powerlessness may be diminished by enlarging their competence, and that in turn can be done by increasing their knowledge. If caregivers are to become more involved they will need to be listened to in order to become better understood. If not, there is the risk that professionals may unintentionally or intentionally influence caregivers to adopt professional beliefs and roles, thereby diminishing their unique 'lay' contribution which is a valuable input.

### **Social Factors Leading to the Possible Compulsory Detention in Hospital of Older People with Mental Distress.**

Social disadvantage and social isolation were identified in chapter one as important risk factors for the onset and maintenance of episodes of mental illness in older people. According to Moen (1996) living alone is a leading indicator of the potential for social isolation while social integration may enable older people who live alone to maintain independence. Social isolation has been defined as

..... “a state in which the individual lacks a sense of belonging socially, lacks engagement with others, has a minimal number of social contacts and is deficient in fulfilling and quality relationships”

(Nicholson, 2008)

Biordi (1998) emphasised that the *quantity* of social contacts should not be the only factor to be considered – equally, if not more important, is the *quality* of contacts which also need to be considered when determining social isolation.

### Importance of Fulfilling and Quality Relationships.

The loss of intimate relationships with spouse and friends, possibly as a result of bereavement or family break-ups are almost inevitable as people age. Harry lost contact with his friends and extended family because according to Jenny `he became threatening to all who knew him`. From Jenny's perspective there is loss in terms of family life – her mum had died and close family and friends stayed away because of Harry's behaviour. Charlotte only had a `close friend` for support – her three sons had disowned her many years before - `John refused to have anything to do with her` – David had emigrated to America and `wont come over` and Steven reluctantly visited stating `if I do not take responsibility, no one will`. Steven answered in terms that might be seen as a duty because even though he states `I don't like my mother`, he seemed philosophical about the difficulties being caught in the middle of caring for a mother and a family who refused to help on any grounds. John's wife Moira sees him in need of support, if not from her then from family and professionals because according to her `I can't watch him all the time`. However, because of this she seemed to identify a role for John to maintain his mental health by `keeping his appointment with Dr Wright once a month` and also `keeping up with the tablets`. Perhaps part of this was an attempt to maintain some independence and be valued for helping himself the best he could. Within some families, there seemed an acceptance of the possible long-term nature of the changes at an everyday emotional level – nothing would ever be the same.



However, being an informal caregiver for a family member can become stressful. For example, relationships marked by abuse and violence, or the fear of it were present prior to assessment in several older people's lives. ASW James said 'Harry was a danger to himself and others, especially his family' while Dr Sands added,

....."he had threatened his wife more than once – and in the end his behaviour got too much for them"

Charlotte's son Steven reported a,

..... "complete breakdown - there was always trouble in the house, you know between mum and dad, always arguing and fighting - the family broke down completely"

Dr Khan said Alice's husband was in a nursing home but,

...."she had become aggressive and there were suspicions Alice had been abusing him"

additionally,

..... "Joseph was totally deluded believing his neighbours were threatening him and his money was being stolen"

Dr Wright said of Charlotte's man-friend,

....."there are suspicions she has become increasingly vulnerable to the input offered by him – there is a general belief that he is possibly abusing Charlotte, both financially and sexually"

The above examples provide evidence of quite different phenomena, that is, older people being abused and older people being abusers and this may be a significant area for further research. Although not specifically focused on older people experiences, according to Goodman *et al* (1997) numerous studies of psychiatric inpatients, outpatients, homeless and mentally ill people have found that a large proportion being treated for mental health problems have at some time been

victims of violent physical or sexual abuse. The long-term psychological effects of victimization may be compounded by adverse social environments and non-compliance with medication. Moreover, people who routinely witness or experience violent events throughout their lifecourse over a long period of time may begin to act violently themselves, as a learned behaviour or reaction to perceived threat from others, which may account for the aggressive behaviour displayed by several older people within this study and so relevant. Good quality relationships with family and friends are important to older people and their caregivers. Campbell (1989) found that people with mental illness, across all age groups, value close friendships, because their family and friends listen to them and regard what they say as valid and important. Good personal relationships are vital for mental health and well-being and if maintained, they may avoid older people becoming socially isolated and help reduce the risk of common mental health problems.

#### The Effects of Social Isolation on Older People.

Forty per cent of older women and 20% older men within this study lived alone for various reasons including widowhood. Michael said `I've been living on my own for years so I am used to it – I like it that way`. Most people are social beings and thrive on contact and interaction with others – but within the qualitative study, 60% of older people were living alone prior to their assessment. Similarly within the documentary study, 68% older women and 56% older men were living alone in their own homes. According to Moen (1996) although older persons can live alone without being socially isolated or feeling lonely, living alone is a leading indicator of

the potential for social isolation. According to Nicholson (2008) there are a few distinct concepts of social isolation, which are lack of social integration, social engagement and social networks and suggested considering those distinct concepts when determining social isolation.

Social isolation can occur at any time during a person's lifecourse but there is a higher prevalence in older adults due to the decreases in health and well-being associated with later life. In the United Kingdom, a study of loneliness and isolation conducted by Owen (2001) revealed that over 12 per cent of people aged 65 and over felt socially isolated. Charlotte did not engage well with anyone whether it was friends or family. Steven said she `repeatedly refused help from carers` and brother John `refused to have anything to do with her`. Charlotte had a neighbour who went in but `there is no one else, that's about it` said Steven. Michael said `I don't like people coming into my flat – I told them to stay away – I don't need anybody`. While in hospital he confirmed `I don't bother with anyone – I stay on my own, I like it that way`. Muriel his sister commented `he's not a good mixer – he just keeps himself to himself`. Katherine said `I live on my own, hardly go out so get lonely`.

Again, from the relatively small sample within this study, it appears one of the key determinants of whether older people are admitted into hospital is linked to social isolation – particularly living alone with little support. Michael, George and Joseph all lived alone but neighbours made the initial contact with services who then

intervened. The over-arching point here is that if society as a whole had more information and knowledge related to possible mental distress, for example, the possible impact of social isolation, intervention strategies could be implemented earlier and hospital admission *may* be avoided. As Nicholson (2008) concluded, when social isolation is experienced negatively by individuals it becomes a problem that requires management – preferably early management.

### **Iatrogenic Effects of the Mental Health System.**

#### **Power Issues Emerging During the Compulsory Detention Process.**

Iatrogenic, according to the dictionary, means arising because of medical treatment which can cover a range of things both good and bad but modern clinical acceptance has tended to focus on iatrogenic effects as more the adverse or unintended side effects or outcomes of intervention. It could be viewed from a broader perspective as any action or decision taken by professionals that, as far as the older person was concerned, had a negative effect on their well-being. If older people and caregivers have experienced the mental health system as harmful to them, in whatever way, then this may deter them from ‘engaging’ with services in the future if necessary. One of the themes to emerge during data analysis was the exclusion of both the older person and family caregiver during the time of assessment, detention and discharge. Several narratives provide examples where older people and their caregivers, often the primary experts on the circumstances surrounding their mental distress, were excluded at times they considered critical and consequently, they felt they should be listened to. Edward’s wife commented a

nurse “explained everything to us” when we arrived at hospital and Alice’s family said they were told “what was going to happen”. However, according to several family accounts, some professionals rarely considered sharing information, particularly at the time of assessment. Harry’s daughter was asked “to leave the room” while Katherine’s son said “their minds are already made up”. Anne’s son stated “nobody spoke to me but it was a foregone conclusion she was going to be kept in”.

Several caregivers within this study experienced varying levels of powerlessness and invalidation in their interactions with mental health professionals. They said that mental health professionals did not listen to what they had to say and rarely asked for their opinions. Harry’s daughter Jenny referring to the time of assessment said ‘we weren’t happy but went along with it’. Jenny continued stating that when they arrived at hospital ‘we weren’t told very much really – we found ourselves knocking on doors and ringing people to see what was going on – I expected more information’. At the time of discharge, Alison added ‘we simply received a phone call from the hospital saying he was coming out – but no one asked us what we thought’. Some caregivers expressed resignation and did not expect professional attitudes to change, while others expressed frustration and sometimes anger at these attitudes. Katherine’s son Robert referring to the assessment said,

... “well from what I can gather, I feel, and it’s only my opinion, their minds are already made up before the assessment and then there is no chance of changing it, that’s it, the medical people are so powerful aren’t they, they can do what they want regardless of what anyone thinks”

Referring to Valerie's treatment Peter commented ` the medication wasn't working and they gave Valerie ECT without informing me – I was angry but my son was furious`. On the one hand caregivers appeared to be in a position of *power* over the older person acting as the `trigger` to them being assessed and ultimately sectioned. On the other hand they experienced *powerlessness* when faced with mental health services.

The sense of vulnerability felt by some older people, for example at the time of assessment, may become exacerbated by poor communication. Barker *et al* (1999) described how knowledge elicited during assessments arises out of conversations that occur between people. However, 73% of older people were reported by professionals to `lack insight` and as having varying levels of capacity at the time of assessment which may have impacted on their ability to communicate. This critical time needs to be considered from a `broader` perspective because arguably, the confusion and uncertainty that may have been present during the admission process may have been compounded by the lack of information given to the older person – they simply did not know what was happening. Several caregivers were in pursuit of information that may have helped them understand the older person`s behaviour which may have implications for policy research, exploring why the willingness to communicate in a meaningful way, is not common across professional groups.

A strong argument for the older person's inclusion at the time of assessment is forwarded by Beresford (2005) who states that modern understanding of mental distress continues to be dominated by medical frameworks for analysis and treatment. However, one particular quality distinguishes the knowledge of mentally ill older people and caregivers from that of all others involved in the field of mental health care - their perspective is experientially based and does not emerge from an intellectual or occupational perspective based on a medically dominated discourse. Beresford (2005) concludes that the knowledge of the older person and their caregivers is primarily based on their direct experience of policy and provision 'from the receiver end' which underpins arguments for the views of older people and their caregivers to be listened to and understood.

#### Problems with Communication – Language, Discourse and Knowledge.

Harry and Josephine's families consistently reported an inadequate level of communication, but possibly it may have more to do with, not the amount of information offered, but the 'language' that is often used by professionals. Professionals stated Harry 'had no insight into his condition and, he lacked capacity' - 'he was suffering from a mental disorder that warranted detention'. Similarly with Josephine, 'she did not have the capacity to make a decision' - 'she had no insight and was having active auditory hallucinations'. These universally accepted forms of psychiatric terminology may be suitable when talking to other professionals but older people may feel excluded from the assessment process *if* the same language is used when talking to them. When asked about the

assessment, Harry said, `there were questions, I didn't know what they were talking about and Charlotte said `I couldn't understand. Anne said `a doctor was talking to me and someone else, I couldn't follow what was going on – it was all confusing to me`. Using language older people are familiar with to describe their problems may leave them feeling relieved that someone has listened and understood them and feeling more empowered to help treat their distress. Some professionals may choose not to explain diagnosis to caregivers for confidentiality reasons. Nonetheless, older people and their families within this study may have benefited if they had insisted on clarification in `plain` English if they did not understand exactly what the doctor was saying. As Trivedi (2010) suggests, in understanding distress there is a need for more sophisticated understandings of experience framed in people's own words, using the language that survivors themselves use.

According to Pilgrim and Rogers (2003) a further important issue is the distinction between `local` and `generalisable` knowledge, whereby older peoples` knowledge is particular and relevant to their mental illness, compared to doctors who tend to apply general knowledge about `types` of mental illness to particular older people, as per the DSM discussion in chapter one. Alice said `I haven't been well for a while now` while Dr Wright said `Alice has a history of cognitive decline with a day-to-day fluctuation`. Rita said, `I haven't been well for a long time though` - Dr Roberts stated `Rita was presenting with cognitive impairment with significant disorientation and had no insight`. Michael said `there was nothing wrong with me



except for an eye problem` while Dr Roberts reported `Michael was showing aggressive behaviour, hypomania with pressure of speech with flight of ideas`. Thus, the inclusion and introduction of both the older person's knowledge into the discussion of mental health brings into the arena a crucially different relationship between experience and knowledge and between direct experience and mental health discourses.

#### Tensions During Treatment in Hospital.

Whilst some professionals within this study believed medication was essential to avoid further deterioration some older people were sceptical about the efficacy of the medical approach, while some caregivers complained about the processes adopted relating to treatment. Dr Wright said Charlotte was, `totally compliant with her medication which significantly reduced her psychotic symptoms` Dr Roberts stated Michael `did not take long to settle – he became fine with his medication`. However Michael replied `they tell you nothing, just kept in the dark, fed medication to keep you quiet – it's all poison, I'm not happy`, which, if true, reflects the dominance of the medical model. Dr Wright stated John's `medication was not working and so we changed it which may not have helped – eventually he had ECT`. John replied `tablets don't work for me and I kept telling them I needed ECT but they didn't listen – they did not give me the ECT early enough`. However, ASW Helen and John's family confirmed several discussions did take place prior to ECT taking place and they were happy with the consultation with professionals prior to any treatment.

Problems relating to poor communication have been discussed above so possibly the reasons for prescribed treatment and any reported side-effects may not have been made clear to some older people. At times, there does not appear to be any noticeable consistency between reports, for example, why some consultants are more than willing to talk treatment through with the older person and their caregiver and yet some are not. The importance of including older people and their families within discussions relating to their treatment cannot be over-stated. It has the potential to have fundamental implications for the understanding of their experience of mental illness and consequently, offers an additional basis for interpretation. In relation to the management of mental illness, the power of lay knowledge to act as a counter to professional knowledge is still relatively marginal. As Pilgrim and Rogers's (2003) conclude, progress in addressing inequality appears slow, with no short fixes, but clearly crucial for reasons of greater participation. If mental health services are to build on the progress already achieved, it may help if they incorporate a commitment that allows older people an increased opportunity to play a lead role in decisions related to their treatment.

#### Power Inequality at Time of Discharge from Hospital.

According to Jones (2002) some caregivers are powerful advocates for their relative's right to live independently in their own homes; others do not want to see their relative exposed to risk and feel they should persuade the older person to accept the 'safe' option of residential/nursing care. Relationships between older people and their caregivers are not always positive, and occasionally there are

conflicts of interest between the caregiver's wishes and the older person's best interests. At the time of discharge, Charlotte said, 'I just want to go home'.

However Steven said staff 'were trying to get her into a nursing home, that's what she needs now, she can't go back home. Rita commented 'I just wish they would let me go home now - but they say I can't'. Her son Brian said 'no she can't go home, she's going into a nursing home'. Agnes stated,

..... "I told them I wanted to go home but they said that would not be possible - when I asked why, they said because of the care I need - I have to go into a nursing home, but I don't want to"

Agnes's daughter Mary commented,

..... "there was absolutely no way mum could have returned home - she couldn't look after herself and I couldn't do it - she needs 24 hour care"

Alice said, 'they said I could not go home - they wanted me to go into a care home, but I did not want to - I can look after myself'. Her son David said, 'it was agreed by everyone, except mum, it would be best if a place was found in a nursing home'. Joseph said I was told,

..... "it would be best if I was to go into residential care - I said no, I wanted to go home, but they didn't give me a choice - they were telling me what was happening - that's the way it works in here"

Joseph's niece commented 'I wasn't interested - I got one phone call telling me he was going into a nursing home and that was it'. According to Stewart *et al* (2005) uncertainties and conflicts around 'place of discharge' have always been a feature of the care of older people. On one hand, placing a person by coercion or deceit in an institution where they may stand little chance of leaving is a fundamental human rights infringement. On the other hand, letting someone go home with poor

memory, impaired judgement and little appreciation of risk may be irresponsible or even negligent. At the time of discharge Hayley the ASW confirmed `Katherine does not have family in the area`. At the time of Rita's discharge she could not return home because the professionals said `she lives alone and could not take care of herself – it would not be safe`.

The question of capacity commonly arises when an inpatient states that they wish to return home after discharge but where staff have concerns about their safety or when relatives insist that a care home placement is required. According to professionals, Agnes lacked insight during her stay in hospital and now

..... “needs 24 hour care, she cannot cook or medicate - it will be best all round if we get a permanent place for her and her family agree”

During her stay in hospital, professionals said Alice `had no insight` and at the time of discharge said Alice

..... “could not look after herself, she may forget to take her medication, there was no way she could return home which everyone agreed with”

Joseph wanted to return home but according to ASW Kimberley had `problems complying with medication so a serious chance of relapse` which may result in re-admission to hospital. According to professionals Joseph `refused to take any medication` and Alice `was `not complying with medication` during their stay in hospital while Agnes had for a long time` refused any help from mental health services`. These were probably significant factors when decisions were being made relating to discharge. As Tehrani *et al* (1996) stated, medication non-compliance is a common factor leading to admission or readmission to mental

hospitals. Stewart *et al* (2005) concludes that the dominant consideration is often 'safety'. This may arise from a genuine concern about welfare but might also involve fear of blame or litigation arising from an adverse incident following discharge. The perceived 'safest' option is usually to discharge to a care home, although it is difficult to know whether someone will really be 'safer' residing in an institutional facility against their will, compared to returning home 'at risk'.

### **Disengagement from Services - Non-Compliance.**

Disengagement is closely linked with medication non-compliance (Mitchell and Selmes, 2007) According to professionals, Charlotte had 'problems with medication' and during her time in hospital 'wanted to go home – she tried to leave at every opportunity'. Similarly Michael who 'had not been compliant with medication and refused all offers of help'. Harry, Valerie, Josephine and Agnes all lived with supportive family members and did not disengage from services.

However, Charlotte's family relationship had completely 'broken down', while according to Dr Roberts, Michael, who lived on his own, 'was not compliant with medication'. Katherine said, 'I live on my own now – my daughter used to live with me but she died, and according to Dr Khan, Joseph, who lives alone stated 'there is ongoing concern relating to his repeated non-compliance with medication'.

Corrigan *et al* (1990) concluded that a person's social circumstances, including domestic situation, such as whether they have someone there to remind them to take their medication, can affect compliance. Dissatisfaction with services and the negative effects of being admitted compulsorily are reported by patients across all

age groups as some of the main reasons for dropping out of care (Ruggeri *et al* 2007)

Living alone has also been found to predict disengagement (Tehrani *et al*, 1996) while being single has also been linked to withdrawal from psychiatric contact (Herinckx *et al*, 1997) Becker *et al* 1997 concluded that having a supportive family is the best way of avoiding a coercive pathway into care while conversely, lack of contact with family has been associated with hospital use. If the older person felt they had been listened to and had a degree of perceived participation in treatment decisions then this may help with engagement and so prevent the chances of compulsory powers being used again. The older person may not fully understand the possible benefits of complying with their medication because they have not been explained to them. Dixon *et al* (1995) defined the engagement phase as developing a trusting relationship between the treatment team and the patient. However, when Michael was asked if he would contact services in future he said `no, I would never go near them again`. Similarly George said, `no, no way, they don't listen to anything you say so why bother`. Helen talking about her discharge plans stated `someone has spoken to my daughter, but nobody has spoken to me about it`. According to Mitchell and Selmes (2007) older people who discontinue medication of their own accord may be reluctant to disclose this to medical staff, and indeed, may not get the opportunity if they are not seen again which highlights the importance of contacting services if necessary in the future.

However, several older people were happy with the service they received including Katherine who, when asked about contacting services in the future said `definitely, I really feel well now`. John said `I can't complain about the way they have handled the discharge`. Hall *et al* (2001) describe engagement as adherence to treatment in terms of remaining in contact with services, collaborative involvement in treatment and openness about difficulties. Whilst the terms `engagement` and `disengagement` are commonly used when discussing the complex relationship between people with mental health problems and the services provided for them, these are rarely defined explicitly. Perhaps the difficulty resides in the complexity of the phenomenon itself, or in the fact that engagement and disengagement are not discrete dichotomous entities. This lack of a clear and widely accepted definition may suggest that attendance is often used as a proxy term for engagement, which from the evidence presented above, is not strictly true. Engagement is much more than simply turning up for appointments. According to Thurgood (2004) from an older person and caregiver perspective, it is more important that services are 'acceptable, accessible, positive and empowering'.

#### Older People's Experiences of Medicalisation.

According to Coppock and Dunn (2010) many drug treatments have been found to produce iatrogenic effects often producing new forms of sickness in those they aim to treat. My remit during this study did not include questions relating to polypharmacy or side effects from prescribed medication but it is common that potential benefits of medication at times are counterbalanced by severe side

effects. From an older person perspective it appears symptoms of mental distress are becoming medicalised. All 15 older people within this study initially received medical treatment with several stating they were not involved in the decision although some had different views on the use of medicalisation. Harry said `I was on the wrong medication, I kept telling them, but nobody listened`. Michael said he was `fed medication to keep me quiet – it's all poison` – they just do what they want, you have no say`. However, John stated, `tablets don't work for me and I kept telling them I needed ECT - it's the only thing that works for me`. Gray *et al* (2005) conducted a patient satisfaction study across all age groups and reported that those prescribed antipsychotics did not feel involved in treatment decisions and stated that they took medication only because they were told to.

Some older people throughout their lifecourse may have had negative experiences while taking prescribed medication including unpleasant side effects and possibly a decreased level of cognitive functioning. This in turn may lead to confusion, possible forgetfulness and an inability to consider the possible value of taking prescribed medication which may result in non-compliance. Forty per cent of older people in the qualitative study did not comply with their medication. Harry said `the tablets made me feel worse` - Michael was partially sighted which may have produced some practical difficulties. There were suspicions that both were not taking their medication prior to their assessment but once in hospital they were fully compliant – possibly all they needed was someone to monitor them while in the community which may have avoided the need for compulsory detention.



Lack of insight may have also contributed to older people refusing to take medication. According to Trauer and Sacks (2000) not only is lack of insight or awareness of having a mental illness commonly cited as a primary reason for non adherence to antipsychotic medications, psychotic patients who lack such insight are at significantly increased risk of further non adherence and hospitalization. Harry, stated “there was nothing wrong with me” while Charlotte commented “there was nothing wrong – I was fine” – both, according to professionals ‘lacked insight’. However, denial of the need for treatment may be a way of dealing with the stigma consequent of a diagnosis of psychosis. John during his lifecourse had a history of hospital admissions and, along with his wife, was fully aware and accepting of his mental disorder – he also knew what treatment he required to overcome the symptoms- the problem was, according to John and his wife, ‘nobody listened’.

The different experiences of ‘medicalisation’ led to several negative comments following discharge from hospital. Harry’s experience in hospital led him to stress he ‘would never contact them again’ while Michael said he was forced to stay in hospital against his will commenting ‘you don’t stand a chance’. John’s wife confirmed the refusal of professionals to listen to their concerns relating to the continued use of medication with John which led to him being in hospital longer than necessary – a point confirmed by Dr Wright. Relationships with the health professionals involved in diagnosing and prescribing can also affect compliance. There were references within Harry’s, Charlotte’s, Michael’s, Josephine’s, Valerie’s and John’s stories to professionals who ‘do not listen’ in areas related to

prescribed medication and Electro Convulsive Therapy. As stated above, people who do not know their practitioner well, and feel unable to trust them completely or ask questions and who are not encouraged to talk about their medication concerns, are less likely to comply than those who do feel comfortable and do ask questions. Charlotte stated she was treated `terrible` and Josephine's son commented `nobody listens` - both, according to professionals were non-compliant and furthermore, did not have good quality relationships with those involved.

These comments referring to professionals not listening reflect genuine concerns for older people and can lead to their exclusion from discussions relating to their care. Although an increased commitment to better communication may not resolve power inequalities on its own, it may help if older people and their families were included and involved in decisions relating to their care and treatment. However, it is apparent that some professionals rarely consider such requests, which often leads to some older people and their caregivers becoming angry and feeling isolated from the process which is consistent with other studies (Shepherd *et al* 1994; Strong 1997) Viewing mental illness through a biomedical lens is limiting in that it gives little consideration to the possible social factors and may negatively impact on the balance of power in the relationship of the older person and the professionals. This may result in the medicalisation of mental illness, the individual, and the family which could lead to a justification of control `for the good of the older person`. According to Coppock and Dunn (2010) there needs to be a more balanced approach to understanding the role of physical treatments for mental

distress, recognising that medication has a potentially useful but limited role as one aspect of the help that those in mental distress might choose to receive.

### **Summary.**

To summarise, I will return to the themes identified at the beginning of the chapter.

The analysis presented here is enriched by the inclusion of the views of older people, their families/caregivers and medical professionals about the issues that are important to them. This study has shown that some older people develop a mental illness as they age, while others grow older with a continuing experience of a mental illness that developed earlier in their lives. An arbitrary age is not a satisfactory criterion to determine the service a person receives. Mental health services must recognise the equal value of all people based on need not age.

However, a needs-based service will require the development of comprehensive specialist-based mental health services for older people to ensure they receive a service that is equal to that received by people under 65 - an approach reflected in the Equalities Act (2010) The nature of mental health problems in later life defines a set of needs that will only be satisfactorily met by commissioning specialist older people's mental health services to provide assessment and treatment for the full range of disorders with a particular focus on reducing the risk of detention in hospital. This recognises both the differences that exist in mental health problems arising in later life and the psychosocial context in which they develop.

In line with Barnes and Maple (1992) suggestion, it could be argued some older people may be detained in hospital and treated for nothing more than the normal sadness and distress that often accompanies old age while other older people with possible diagnosable problems are not accessing treatment because of barriers to receiving care. Aggressive behaviour, described by caregivers and professionals throughout the narratives, often precedes mental distress and may also be present at the time of assessment. It must be increasingly difficult for families and caregivers because their perceptions are often driven by insufficient knowledge about specific mental illnesses relating to behaviour and mental distress. Additionally, they may have difficulty recognising what is wrong with the older person, particularly if the onset of the problem has been gradual. Combining this with their limited understanding of services available may help explain why some delayed contacting appropriate services at an early stage. It is not my intention to over-simplify my argument here, that is, if caregivers were better informed and professionals communicated better, then older people would engage with services, receive help earlier and all would be well. Rather, although my argument may be viewed as radical, it is supported by several authors including Jorm (2000) who concluded that many people cannot recognise specific disorders or different types of psychological distress which points to the challenge ahead. Improved societal awareness of mental distress may 'trigger' early intervention and avoid admission to hospital. If there are to be greater gains in prevention, early intervention, self-help and support of others in the community, then we need a society in which basic knowledge and skills are more widely distributed to aid early recognition of mental

distress. In policy terms, it is important to determine whether education and intervention initiatives aimed at reducing compulsory admission to hospital should target resources much earlier in the life course.

The results suggest that some older people whose relationship with professionals and families had broken down may become more engaged if they had felt listened to and had a genuine say in decisions about their care. This may have helped facilitate the making of informed decisions about treatment options. For many older people, (Harry, Michael) moving away from an exclusive focus on medication may be a crucial element in improving therapeutic relationships with both professionals and caregivers. There are several examples within this study where care was undertaken by families reluctantly (Harry, Charlotte) but it appears that family relationships are being governed by historical obligations and based more on relationships built up over a the life-course. According to Lefley (1996) progress through the life course is one factor that changes need and the evidence for best effectiveness and outcome for older people has been shown to be when there is a greater level of family acceptance of both the older person and the situation as it is. However, for acceptance to take place there will undoubtedly need to be a shared understanding of the care required by professionals, the older person and the caregiver, but this may not always be possible which may lead to possible conflicts within relationships, for example at the time of discharge from hospital.

Replacement of these relationships with new and meaningful activities may often be difficult for some older people and often result in social isolation. Increased

compliance with medication is associated with stable family circumstances and evidence suggests that family and social support make engagement with services more likely (Kampman and Lehtinen, 1999) The loss of independence, that is, being confined to the role of mental health patient may have contributed to the older person's non-compliance and disengagement. This may be strengthened if older people are given the opportunity to be actively involved in making decisions about their treatment and so become more accepting of their illness.

One of the over-arching themes to emerge from this study has been the expressed power inequalities often found present during the compulsory detention process (George, Katherine) There was often a tendency for some professionals to consider symptoms as a medical problem, treat immediately with medication and so overlook what might be going on from a social perspective for the older person that could have triggered these symptoms. Therefore, as Coppock and Dunn (2010) point out, the assessment process becomes heavily orientated towards the *form* of the distress rather than the *content* and *context* of the distressing experience. Some professionals approached the older person's assessment from a medical model perspective and consequently, their attention is drawn towards the older person themselves – the individual, which could be argued is not holistic and so not person centred. On the contrary, it relates to the assumption that the `problem` lies *within* the older person. According to Pilgrim and Rogers (1996) such an approach detracts from a fuller understanding of possible social dimensions that may relate to distress, for example social isolation, living alone

and family conflicts. An unconditional respect for the views of all people involved in the assessment process may inform the nature of the older person's care and so contribute to a better understanding and acceptance and hence avoid pitfalls around non-compliance, dis-engagement and possible re-admission to hospital.

The primary challenge to those professionals who adopt the medical model approach is to recognise the power they wield – the power vested by society and by individuals simply in the position they occupy as psychiatrists, doctors, approved social workers or therapists. They may need to establish and maintain good quality relationships with people whose response to such power may not be automatic trust in their authority – which may lead to disengagement from services. The medical model approach to treating older people with mental distress can leave some feeling powerless while the professionals, through recognition and acceptance, have an opportunity to empower older people and their caregivers. An essential step in such empowerment is recognising that older people have something to teach professionals. Older people and their caregivers often have great insight into the difficulties they live with every day and can also educate about the context of their problems, for example their lives current and past.

Within this study, communication with professionals was especially difficult and marred by `power over` issues. Sixty-six per cent of older people within this study complained of a lack of communication during their admission in hospital which was often confirmed by caregivers. Older people need to be well informed about

the options in a manner that is accessible and not obscured by jargon. This may require a cultural shift and more work with those professional groups who are resistant to change. The alternative to this may see older people disengaging from services. According to Priebe *et al* (2005) a lack of active participation in treatment decisions is one of the main reasons for disengagement because people felt alienated when professionals fail to acknowledge their experience and their view of illness. The issues of poor relationships and the passive role of older people were amplified further when it came to the experience of detention. Thirty-three per cent of older people said they would not contact services in the future for example George who said, 'no way, they don't listen to anything you say so why bother'. Charlotte said, 'there is no way I would trust them again, never, after the way they have treated me'. These actions could be viewed as 'iatrogenic effects of the mental health system'. The first line of treatment for all older people within this study was medication even though several older people objected, most especially John who from experience knew prescribing medication was the wrong decision saying 'tablets don't work for me'. John was willing to engage but nobody listened. The focus appeared to be on biological explanations and ignored the possibility that John's mental distress may be the result of his former life experiences. Some professionals may consider giving up some of their power by allowing older people to be involved in their treatment regime. A move away from controlling the older person towards exploring suggestions made by the older person and their caregivers appears essential in facilitating greater engagement without an exclusive focus on medication.



## **Chapter 8.**

### **Reflections on My `Research Journey` - My Experience.**

#### **Introduction.**

According to Primeau (2003) reflexivity is a qualitative research strategy that addresses our subjectivity as researchers related to people and events that we encounter within the study and furthermore, it helps address the subjective nature of the research account as a narrative constructed by us as researchers. It can also enhance the quality of research through its ability to extend our understanding of how our positions and interests as researchers affect all stages of the research process. The aim of this chapter is to offer the reader my reflections as a researcher on my doctoral journey – my `lived` research experience. I will consider what I have learned about the research process and also consider issues I was faced with and how I resolved them. As my study progressed there was a need for a change of methods and the frames for analysis which I will discuss. Finally, I will reflect on my tendency at times, to see a situation as a `practitioner` rather than a `researcher` - and how I dealt with this as a phenomenon.

Although fundamental changes happened during the research journey, it was not until I reached my destination that some of the changes become apparent. The changes that occurred were ontological as well as epistemological - changes in `who you are` as well as `what you know`. From my experience, these changes were influenced and shaped by the authors I encountered at different stages of the study because as I set out on my research journey I became fully aware that I was also embarking on a journey that included reading relevant literature. However, these changes in thought and direction

helped me to make sense of some of the experiences a student might go through, not only as a `novice` researcher but, in my own case at least, as one who, in seeking to continue and develop my research skills, encountered new possibilities for beginnings.

### **The Research Process - Issues Raised During the Research Process.**

According to Batchelor and Di Napoli (2006) a PhD is perceived as a status-bringing 'object' to be achieved - the 'book' to be written and is the stage at which, ontologically, the most passion for the project is felt - motivation and excitement are high, along with some trepidation for the things to come. A sense of expansion is experienced, as one feels excited about starting a new study where the topic is usually close to one's heart and mind. Before setting out on my research study, I recognised at a very early stage that undertaking a doctoral degree required a specific writing style, possibly less personal than the one I had imagined it to be. Not only did I need to learn how to research but also how to write in forms that would be acceptable both to a given epistemological community and within doctoral parameters.

### **The Early Days of my Study.**

I had recently completed a taught Masters degree with no empirical content, for example one-to-one interviewing, to speak of and yet, during my first meeting with my supervisors I was being made aware of what the next four years within academia would hold for me. I was presented with a `scientific review` of the sparse amount of previous research in my study area and also the methodology, methods and frames for analysis to be adopted. The whole approach had been pre-set, with the aims and objectives outlined within the

meeting which seemed rather unusual to me – I was expecting to be part of this process – it may have given me a sense of `ownership` at a very early stage of my study. I felt as though I was being constrained because all the parameters had been decided, a process I was excluded from. If I would have been allowed to contribute, I would have suggested a more prominent role for the caregivers within the study – who cares for the caregivers; what their experience was and also, what support was available, and offered to them? Additionally, although time consuming, I would have suggested setting up a focus group for caregivers which may have produced some good quality data and possibly impacted positively on the overall study. Using different sources for collecting data can help check your findings. For example if I could have combined one-to-one interviews with data gathered from focus groups then, following analysis, if the data from these different sources pointed to the same conclusions then maybe it would give more confidence in my results.

### **Interviews Dilemmas!**

As part of my “contribution to new knowledge” I was expected to conduct sixty interviews with consenting participants. At that particular time, I did not fully comprehend the consequences of sixty interviews, the sheer amount of data this method would produce. I could have been told I would interview twenty, thirty or even a hundred participants; the full realisation of what this entailed did not register. As my study progressed, I did speak to my supervisors about the amount of data I was gathering and it was suggested that once I thought I had reached `saturation` point, that is, nothing new was being revealed during the interviews, it would be a good time to stop and begin the analysis.

However, I found each older person’s story different and individual and as

such each revealed data that, from my perspective, would add to my thesis. Some older people and caregivers were happy, some sad, many were angry at being detained and yet others felt they needed time in hospital to aid their recovery. Several had good relationships with the professionals and yet, once again, several were far from happy with the way they had been treated – as stated the experiences within this ‘multiplicity of narratives’ were all different. Every older person had a story to tell about their experience which was unique to them.

### **Who Holds the Power during Interviews – and Why?**

In practice, I considered the older person, and to a lesser extent, the caregiver to be the experts – they were the people at the ‘receiver end’ – they had personal experience of compulsory detention. However, I felt as though I was in a fairly powerful position – I was the academic, the principal investigator, the PhD researcher and felt I was in control - it gave me a ‘power over’ feeling during the process. However, when I was interviewing professionals, the consultants/doctors and approved social workers, from my experience, the roles were reversed – many had been practising for many years and as such they had far greater knowledge of mental disorder, the process of admission and detention – in short how the system works. What made me feel this way is difficult to explain – maybe I was showing too much respect to the professionals because of the positions they held – but I must add that I was also very respectful towards the older people and their families. I remember vividly my first interview, waiting outside Harry’s house. I felt nervous, although confident; would I talk too much; how would I be received, did he really want me to be there? In retrospect my perceptions were unfounded –

once we got talking it did not feel like an `interview` situation but more of a conversation which found its own route – one topic seemed to lead into another, but I hasten to add not all interviews turned out that way.

Similarly when I was waiting to interview the professionals, I again felt a little nervous interviewing powerful people with vast amounts of knowledge. I was fearful of showing my ignorance by not being able to partake in a conversation around older people and mental disorder. This is only a personal perception but I feel on reflection that several of the professionals were disinterested. I got that feeling when only one replied to my initial request to partake in my study and I felt that again during several interviews. Some had `made time` for me during their lunch breaks and so were eating sandwiches, checking diaries, answering telephones and looking at their computer screens during the interview. They were `physically` present but `emotionally` absent. Their `minds` were elsewhere and I got the feeling some did not want to be there; possibly they had done it so many times before. At times I felt their responses to some of my questions were rather defensive possibly because they viewed me as a `threat` to their dominance in the field – a researcher possibly advocating the use of a more person centred social approach to treatment while they continue to rigidly adhere to the medical model.

However, I could not help feeling that allowing older people to provide narrative accounts of their lives and experiences of compulsory detention may help redress some of the power differentials inherent in the research enterprise and might also provide good evidence about the everyday lives of those who have experienced compulsory detention and the meanings they

attach to their experiences. According to Denzin *et al* (2000) if we are to understand the social world and help meet the demands of phenomenology, we must produce explanations that are grounded in the subjective experiences of those people who experienced a particular phenomenon. At the same time, we must not simply deliver descriptions of states of minds; social science must understand why and how things happen, and this must refer to the way people think about these phenomena – in my case the older person's experience of compulsory detention.

However, as explained earlier in the thesis, several interviews with older people did not produce data that could be viewed as 'good quality' - an unanticipated problem and at times I did not feel I was gathering the 'real' lived experience of the older person. Consequently it was not as phenomenological as I would have liked or anticipated. Good quality responses that address my questions focusing on their individual experiences, I feel, may have strengthened my thesis – but at times it was not to be. There may have been several reasons for this. Was the timing of the interview the right one – possibly not? On reflection this may have been the case; it was the right time for some older people but not for others – but when studying a phenomenon such as mine, is there ever a 'right' time? If I was starting again, I would keep in closer contact with ward staff and families to enquire about the older person. At that particular time did they feel the older person was able to take part in an interview relating to their experience in hospital?

### **So What Might have Helped?**

I have mentioned earlier that as a `novice` researcher I may have benefited from research training in professional interviewing and also techniques when interviewing vulnerable older people. A study by Mowlam *et al* (2007) which focused on abuse and older people reflected the need for specific training in this area. The team of researchers were all experienced in conducting interviews on sensitive topics and with potentially vulnerable respondent groups. In addition, they were given additional specialist training and coaching to prepare them for interviewing on this specific subject from colleagues at King's College London and staff at Action on Elder Abuse. At times I felt a form of resistance from some older people to talk to me – several thought I was a doctor and consequently may have felt angry and disappointed that services had let them down. I accept the older person may have still been experiencing some cognitive problems or they may have felt intimidated or a little scared. In hindsight, if more time had been available, I could have possibly interviewed those older people again at a later date which would hopefully have contributed to the phenomenological approach.

### **A Change of Methodologies.**

#### **The Research Questions.**

It is of fundamental importance to ensure that the research questions relate directly to your methods and data. My study started from pre-set questions framed by others and these guided my original research. However, the very nature of a PhD often dictates that when you write up your doctoral thesis the research can take on a different shape, which happened in my case although initially, I retained the same research questions. There was a need to change

the questions slightly so that there was more coherence between them and everything that followed. It seemed a bit strange to have to do this retrospectively, but I needed to ask myself “What research questions have I addressed?” During the course of a supervision that was held at a late stage of my research journey, there was an agreement that there needed to be an empirical question that specifically focused on the experience of compulsory detention of older people and their caregivers. It was felt that the original questions could have been addressed from information held in medical records at the Queen Elizabeth Psychiatric Hospital. Issues relating to social circumstances, treatment and outcomes following discharge from hospital were held on the hospital computer system.

To conduct a phenomenological study that gathered data relating to the `experience` of older people it was mutually decided to add further questions. What is the `lived` experience of compulsory detention for older people, families/caregivers? How were they treated at the time of assessment, during their time in hospital and at the time of discharge? How was the relationship between the older person, their families and the professionals? By including these questions important issues were addressed. The shift from pre-set questions that could be answered through documentary data to a more interpretative approach requiring engagement with individual `experience` I feel was a positive one. From my perspective, allowing older people who had personally experienced compulsory detention in hospital to describe their experience would provide a more reliable and valid study rather than a purely documentary analysis.



### Data Collection Strategy.

One particular change was the approach to getting to the point where I could collect data; the actual interview stage. I did not anticipate the `poor` response I would receive after sending out my application packs possibly because I was a `new` researcher I thought potential participants would be more than willing to take part in my study. However, within the following four weeks I only received one response from the professionals and none at all from older people or their families. To overcome this, I adopted a more `direct` approach - I rang the personal secretaries of the professionals and made an appointment to meet them during their `working` week so I could explain in person the nature of my research and why their involvement would help. From a personal perspective, qualitative research can add a critical component to the psychiatric discipline and consequently, there remains a need for psychiatry to engage with researchers, to justify, challenge and critique its foundations which may allow us to become more reflexive and creative both in practice and research.

My information packs contained eight pages of details outlining my research and consequently some potential participants, for example older people and their caregivers may have considered it as `junk` mail and not bothered reading it. I contacted ward managers and asked them to notify me when older people were being discharged from hospital whereupon I went to the hospital and spoke to them personally and asked them to take part in my study. I also enquired about contact details for family members so I could get in touch and ask for their participation. An important point needs to be made here. I contacted the Ethics Committee to inform them of my change of

approach and also justified my reasons for doing so. Although my initial approach did not work out as I would have liked I identified the problems early on and changed them and it worked. The value of one-to-one recruitment should not be under-estimated. Recruiting participants is often a challenge, for a variety of reasons, including the often delicate nature of working with vulnerable populations. Rather than meet the older person at the time of the interview, it was beneficial for me to meet some of them on the hospital ward and explain to them, and their caregivers if they were there, what the study was about and so how the findings may help them in the future. It seemed to 'break the ice' as it were and so make our second meeting, the interview stage a little less formal – they knew I was coming and why.

I found ward managers to be the most approachable professionals during the course of this study and feel the qualitative element would have been strengthened further, if interviews had been conducted with them. Ward managers are 'front-line staff' who are active in the care and treatment of older people and consequently, they may have had a lot to offer the research process. They are experienced 'hands-on' professionals, who are highly knowledgeable about the assessment, diagnosis and treatment process, as well as the personal and social circumstances of the older person. Although some ward managers may have a clinical background, I feel their perspective may have been productive and also added a better balance and enriched the narratives. One further weakness with the interview approach is it provided data for a 'particular situation at a particular time', where there may be good reason to believe that the phenomenon I was exploring had been evolving for many years during the older person's lifecourse, and furthermore, in some

cases, may prolong for many more years - hence my recommendation for a longitudinal study.

### Frames for Analysis.

Part of the initial format for my research indicated a cross-case thematic analysis would be adopted within my study, which at the time seemed suitable. My data originated from interview transcripts and required sorting to represent major themes that described the phenomenon being studied. A decision I, as the researcher, needed to make when analysing data was whether to analyse the interview data obtained from each participant independently or whether to use cross-case analysis. However, as my study progressed approaches to methods changed as I engaged more with various authors advocating the use of different methods of analysis. One author was Smith (2009) who advocated for the use of Interpretative Phenomenological Analysis (IPA) emphasising that the founding principle of phenomenological enquiry is that experience should be examined in the way it occurs by involving the careful examination of human experience.

Unfortunately this unanticipated `change of direction` happened after I had completed my data collection. Although I could go back to the data and try to extract more from it in terms of applying the IPA approach, this inevitably became limited because my interviews were complete and obviously I could not go back and redo them. However I revisited the data and viewed it with an IPA 'lens' which was inevitably difficult. Nonetheless, IPA allowed me to adopt a more analytical procedure by providing the framework for moving from single case studies to more general statements while still allowing me to

retrieve particular claims for the participants. If I was starting the study again then, on reflection, I would adopt the IPA approach from the outset. However I would probably not conduct as many interviews because the larger the sample the more selective you need to be when choosing extracts – the more participants the more data gathered.

IPA was particularly suited to this study as it allowed me to explore individuals' experiences of hospital admission, understand how they made sense of their experiences and what meanings the experience held for them through interpretation of their accounts. IPA also acknowledges the part the researcher plays in accessing and understanding the individual's experience and the interaction between them and employs the use of a 'double hermeneutic' - the researcher making sense of the interviewee making sense of their experiences (Smith, 1996) On reflection, my original drafts using IPA were too descriptive but as I repeatedly reviewed the chapter I feel the balance between description and interpretation improved noticeably. In summary, I did contact Jonathan Smith directly on several occasions for his thoughts and his comments were most helpful. He said - 'if the interview material is centre stage and the idea is to illuminate this with other things you know then what you are proposing is possible - as long as it is done carefully and does not detract from the participants accounts. However, he added the interviews must be rich enough to allow experience to come out by paying close attention to the participant's accounts and emergent themes.

### **Practitioner or Researcher.**

Prior to commencing my interviews I anticipated that the responses to my questions would be expressed in different languages – the professionals referring to symptoms and clinical diagnosis while older people and their caregivers would respond more in lay terms. During the analysis stage of the writing up process, I considered a continual focus on the `language` to be used needed to be maintained. It was important to remember my audience. However, at times, and on reflection, I was guilty of adopting the `language` of the practitioner rather than the researcher. For example, during professional interviews it was common for terms `lack of insight`, `lacked capacity` and `non-compliance` to be used to describe an older person's cognitive ability, particularly at the time of assessment. I did not consider if this type of terminology was appropriate. Should I keep the language as simple as possible? I simply reported answers to my questions literally as they were told to me. In hindsight, it may have been more appropriate to report my findings in a plain and clear manner but I was also conscious of being able to convince my audience of my knowledge within my research area by including some complex terms. I was aware of the level of presentation a PhD thesis demands.

### **Summary.**

To summarise, I would like to consider my personal growth as an academic and what I have learnt from my experience. Without doubt the phenomenological approach to help understand the older person's experience of compulsory detention was, from my perspective, the correct one. Enabling older people to talk about their individual experiences has produced an

account that advances our limited knowledge of this phenomenon. In hindsight if I could have anticipated some of the problems I experienced then it may have allowed me the time required to interview some older people for a second time and collect data that specifically addressed the older person's experience at a given time. In an interview situation, power can be seen as something that is created and that shifts between the interviewer and the interviewed. Reflexivity is involved when we as interviewers attempt to look at a situation or a concept from various perspectives.

As Bryman (2004) indicated, it is particularly important to consider some of the distinct power relations that might exist between less experienced researchers and professional subjects as this can significantly help the former to prepare for and conduct these types of interviews. I felt that I had prepared fully for all my interviews but this may be an area I need to reflect on a little more. Although my research training was quite thorough during my postgraduate years at university, including the 'theoretical' approach to interviewing skills, one thing it did not offer was a 'practical' approach to the various techniques required when interviewing different participants, in my case vulnerable older people, caregivers and professionals.

With the benefit of hindsight, pilot interviews with professionals could have been undertaken and may have been beneficial but may also have produced 'other' problems. Some professionals may suffer from 'research fatigue' and will be less likely to contribute if they have participated in what they perceive to be a similar study. Although pilot research is strongly encouraged within the social science literature (Yin, 1989) states there is very little guidance

concerning whether interviewers should be encouraged to conduct pilot work on elite members. Peabody *et al* (1990) suggest that researchers should ask their questions to colleagues and friends before posing them to elite groups which can help to clarify and refine questions. However, I am unclear whether it is encouraged to do pilot work with this group. Indeed, are any researchers encouraged to conduct pilot work with elite members? If the answer to this question is 'no' because of elite time pressure, then does this not lead to potentially poorer quality questions since they have not been pre-tested? There appears to be a lack of guidance concerning pilot work on elite members.

In the final analysis, use of reflexivity should eventually lead us all to the same conclusion as that reached by Haynes (1999:670) when she reconsidered the statement, "You are the writer of your own story - we all create our own life stories, using and relating only the memories that seem most relevant, serve our purpose or those we are prepared to share at the time of telling". In a similar manner, I have shared selected reflexive accounts from my research to demonstrate use of reflexivity in qualitative research as a strategy to address our subjectivity as researchers and serve as signposts for readers about what is happening throughout the research process. Within this chapter I have reflected on the research process but I feel that in conclusion, a reflection on my personal development is appropriate. The emotional challenges experienced throughout my field work year and beyond were not something which I had seriously anticipated. Naively, I never contemplated that listening to the stories of others, through which tales of exclusion, loneliness, and often great anger and sadness were not uncommon, would be

as difficult as it turned out to be. For several days following particular interviews I would often think about the people I had interviewed; how/if they were managing; the impact mental disorder was having on their lives; the often volatile relationships both between families and with professionals.

To conclude, writing this thesis has not been easy – three drafts on and I'm ready to be exposed! As researchers we collect, gather, manage and analyse data, but rarely reflect on how data *impacts upon us*. We may also experience a range of emotions, from feeling restrained to powerless, powerful, fearful, sad, joyful, and frustrated, meaning we carry out extensive emotional work (Dickson-Smith *et al*, 2009) – yet we rarely share it. While I can accept that both my research and my situation may be unique and that the themes within this thesis may not be relevant to everybody who reads it, it does highlight a need to reflect on our research experiences and share these as a community. My coping strategies got me through but there may be better ways and I suggest we can find these in one another. Sharing our emotions, journeys, management/coping strategies and thus creating informal support networks, I propose, may just be the answer towards lessening the burden of emotional work we all experience throughout the research process.



### **Conclusion.**

The principle aim of this study was to explore the individual experiences of older people who became subject to the use of the Mental Health Act (MHA) (1983) and, in doing so, provide answers to the questions referred to in the introduction.

- **What are the social and personal antecedents of older people leading to compulsory detention in hospital?**
- **How does power operate between different participants at the time of assessment and while detained in hospital?**
- **What are the outcomes following discharge from hospital for older people?**
- **What is the `lived` experience of compulsory detention for older people, caregivers and professionals?**

The differing perspectives offered by participants within this study suggest people can experience the process of assessment and detention differently. What has been uncovered is that there is no one `right` perspective but this does not reduce the value of this research study. Indeed, the research has provided an opportunity to understand the complexities of research in this area, including the ethical and governance implications and the appropriateness of the methods adopted for data collection and analysis. I will initially address the approach to the research methodology before articulating important issues that emerged during the research process, including the impact of detention on the older person and family caregiver and the suggested directions for future research. The conclusions are drawn from interviews with older people, their caregivers, doctors and ASWs, but I do not assume that their views are representative of all mental health service users, doctors or ASWs. However, It is their views that underpin the validity of this study,

not least because they are grounded in their experience of the use of the MHA (1983) Although the interpretation of both the older person's and their caregiver's experiences of detention were important, the study has also provided the opportunity to gather different perspectives as voiced by the doctors and ASWs and consequently, it was important that the significance of these experiences were not ignored.

### **Justification for Mixed Methodology Approach for Data Collection.**

The principal aim of the documentary study was to explore in detail the frequency and distribution of compulsory detention as experienced by older people within the South Birmingham area and consequently, I decided a quantitative approach was suitable which served several purposes. It allowed me an important insight into the phenomenon to be explored which then enabled me to describe in detail the 'size of the problem' and so explain what was happening, but not why; that would follow later within the qualitative study. Although I was applying the research strategies separately, they were progressing 'side by side', and often, both methodological traditions complemented and informed each other to help answer the research questions. Analysis of the documentary data helped generate a 'view' of the phenomenon I was exploring by constructing particular images of older people and provided me with a base for interpretation. For example it provided an insight into the social circumstances and gender differences of older people prior to their assessment and where older people were admitted from and discharged to following their time in hospital.

The qualitative study had an emphasis on seeking the views and perspectives of all participants who willingly agreed to take part in this study. My approach to contacting older people and caregivers was eventually successful considering I adhered to all the ethical and governance criteria and eventually interviewed the intended numbers of participants. My information packs contained easy to read information but I feel professionals, who will be conversant with the research process, may have found it too `long-winded` and decided not to read it and as such I needed to change my approach which proved successful. Older people and their caregivers had important unanswered questions that had emerged from their experience of detention and in my view a qualitative approach provided an opportunity for all participants to express their views relating to their experience of detention. Qualitative research is highly contextual, with data being collected in a `real life` setting and often, over a long period of time, which was the case within this study.

Punch (1998) states that the qualitative approach extends beyond giving a mere snapshot of events and not only highlights how and why things happen, it also incorporates the participants` emotions. As suggested in chapter one, the medical model often provides a safe target for the depth of feelings and emotions that existed within older people and caregivers. These expressed emotions would not have been witnessed first hand if, for example, a questionnaire had been forwarded to participants. The personal emotions that emerged from the one-to-one interviews, for example Harry's, Michael's, Charlotte's and Josephine's

experiences would not have been captured if another method had been adopted for collecting data. Some academics may suggest a focus group may have been beneficial, which I would possibly agree with for the caregivers, but apart from the practical and logistical implications older people may not have felt comfortable speaking about their personal, possibly private and confidential experiences within a group rather than within a more private environment, chosen by the older person.

The advantage in conducting one-to-one interviews was that they allowed participants to express their `lived` experience of detention in a manner of their choosing. Interviews were conducted at a pace that suited the participants to afford them the opportunity to express their feelings and prejudices relating to incidents around the time of assessment and detention. The purpose was to explore in detail specific topics relevant to the interviewee's knowledge and to the research questions and objectives underpinning the focus of the research project (Silverman, 2004) However, I found informative interviews were often, in some way, reliant on participant determination for the `tone` and quality of the interview. Although interviews can be a highly `fruitful` manner of exploring topics with which participants are familiar, from my experience they were not so `fruitful` when interviewing some older people. As Bowers (2009) suggests the voices of older people who need a lot of support are often absent - other people for example professionals or family members speak for them.

### **The Use of Interpretative Phenomenological Analysis (IPA)**

Within this section I will describe how I applied IPA within this research study. The central aim of this study was to explore the experience of older people who became subject to the use of the Mental Health Act (MHA) (1983) IPA is applied to interview data and so I needed access to participants who had experienced the phenomenon in question. I had interviewed 58 people in total who had experience of the use of the MHA (1983) and as mentioned earlier, on reflection, I now consider the number of participants too many because of the amount of data collected. However, Smith (2009) does state that `rich` data is required for the use of IPA and from the narratives it can be seen that several interviews with older people did not collect data that could be described as `rich`. However, on reflection by conducting the number of interviews I did with older people allowed me to gather enough `rich` data to adopt IPA as my approach to analysis. As Smith (2009) concludes, there is no right answer to the question of the sample size. It partly depends on several factors including the degree of commitment to the case study level of analysis and reporting, and the richness of the individual cases.

Smith (2009) confirms IPA can be used to develop in-depth descriptions of human experience and is suitable for single cases or an exploration of themes shared between cases. The single-case study could then be written up as a narrative account, but more commonly it would be necessary to move on and collect more data from additional cases. In relation to the latter option I repeated the analysis of each case in turn. My completed interviews produced 15 cases which allowed me

to conduct a cross-case analysis – analysing the first case before moving onto the next and noting themes in the process. It is a key commitment of IPA that analysis should be developed around excerpts from the data which is the approach I adopted by highlighting text from my narrative chapter to help illuminate particular themes that emerged from the interviews. IPA is phenomenological in that it seeks an insider perspective on the lived experiences of individuals and interpretative in that it acknowledges the researcher's personal beliefs and standpoint and embraces the view that understanding requires interpretation. In summary, IPA has allowed me to provide a valuable insight into the lives of people whose voices may not have otherwise been heard, or whose experiences were ignored, or at times constructed quite differently by mainstream theoretical models. Additionally, it has afforded illuminating perspectives upon personal experiences, relationships and processes, as well as professional interventions and contexts. I have found the process exhilarating and demanding, but most of all worthwhile.

### **The Research Questions.**

#### **1) What are the social and personal antecedents of older people leading to compulsory detention in hospital?**

Adverse social circumstances, including isolation and a lack of good quality social relationships were identified within the previous chapter as possible antecedents to mental distress. Nine (60%) of older people were living alone prior to their assessment which often leads to social isolation. For some older people (Michael, Charlotte and Joseph) living alone and possible isolation may have persisted throughout their lifecourse – for others, the experience of ageing, possibly

bereavement or family circumstances, may have resulted in them living alone. According to Rogers and Pilgrim (2003) vulnerability is increased when older people live alone and when possible social isolation increases which will have implications for both the older person and their respective caregivers.

Social isolation can be defined as the absence of relationships with family or friends on an individual level and with society on a broader level. Prevention may be one approach to avoiding social isolation becoming chronic by addressing the needs of groups that are socially excluded and at risk. However, the success of such measures depends on creating a new climate in which the possibility can be better managed by encouraging social inter-action. Furthermore, Victor *et al* (2009) suggests the impact of loneliness depends not on the quantity of social interactions a person experiences but the extent to which these satisfy the person's subjective need for social connection. While isolation and loneliness are problematic for some people in old age, it is important to remember the 'pathways' to these feelings of isolation. According to Victor *et al* (2009) rather than 'artificially' trying to develop social links, we might be better advised to try to ameliorate the negative effects of structural factors such as income, transport problems and the ability of older people to maintain their existing relationships and participate fully in society. As discussed, loneliness is not an inevitable part of old age, but can occur at any time throughout the life course but is more likely to affect older people because of bereavement or ill health.

Hence, care needs to be focused on key life events that if properly managed can prevent mental health problems. As people get older they experience life events, for example the loss of a husband, wife or partner that can impact on their health and well-being. Older people who have opportunities to leave their homes, meet others and build relationships by engaging in activities can lead fuller lives.

Practice implications for older people will include the importance of maintaining close relationships with family and friends and strengthening links within the local community to help build a feeling of social 'connectedness'. As an example, befriending schemes where older people are visited by others can identify whether they are at risk or if their behaviour has deteriorated. Support from befriending is a crucial way in which the wider community can keep in touch with these changes and provide the basis for any necessary intervention by care services. These forms of personal connection can provide the crucial insight that can then inform health and social care professionals. *The National Dementia Strategy* (2009) states that improved services in people's own homes must be available for people living alone, but possibly the strategy should not simply apply to people with dementia but all older people with any mental disorder, especially those living alone.

Effective management of several older people (Harry, Michael) was often hindered by a number of practical difficulties, not least, gaining access to actually see them, especially those living alone. Referrals for mental health assessment were prompted by neighbours or family members as the degree of self-neglect, unusual behaviour and verbal aggression became a risk. One of the main obstacles to



receiving appropriate care identified in this study was the older person`s (Harry, Charlotte, and Michael) reluctance to seek help and their resistance to medical intervention when it was offered because, according to professionals, they were in denial which resulted in them being referred in crisis. This is a time when arguably, intervention strategies should be implemented and a more co-ordinated approach at the local level to target the most vulnerable. In total, 46% of older people had a recorded history of mental illness and possibly, if timely intervention had taken place, compulsory detention may have been avoided. Charlotte and Michael both had a mental health history so with closer monitoring from a community mental health team, then possibly detention could have been avoided. Edward and John`s experience provide examples of good practice but the overall picture was one of inconsistent service delivery.

Mental health services getting involved at an early stage and not, as referred to by Josephine`s and Katherine`s sons as `getting involved when it is too late` may provide positive support to older people who are distressed. Evidence does exist to support this observation. Creer (1975) explored the problems faced by relatives of people with schizophrenia across all age groups, and levelled a great deal of criticism at services that were available concluding relatives often felt that help had not been available until `late in the day` when traumatic compulsory hospital admission had taken place. Within this study, the provision of services for some older people was focused on providing intensive, costly services once problems arose. Shifting the emphasis to intervention and providing lower level services, for

example regular home visits before older people reach crisis point requiring intensive needs may have resulted in an alternative to compulsory detention at the time of assessment and would have been in line with a more person centred approach to care.

According to Brown and Harris (1978) older people are more likely to lack a close confiding relationship - a vulnerability factor for depression. George, Michael and Joseph did not have close family support and although Charlotte did have three sons, relationships had broken down completely. Harry did have a `close` family but relationships deteriorated quickly after his wife died – his daughters cared for him out of duty. Several other families either would not or could not provide the required care – which could produce the `revolving door` scenario whereby older people are discharged from hospital simply to be re-admitted some time later. According to Rogers and Pilgrim (2003) contact with relatives, friends and the wider community is beneficial for the mental health of older people. Addressing the needs of the growing numbers of older people with mental distress, especially those who live alone must be a policy priority. More investment is required to ensure availability of quality services to make it possible. Long periods of loneliness and social isolation has implications for some older people, often leading to the onset of mental distress which may then contribute to a decision to admit them to hospital.

## **2) How does power operate between different participants at the time of assessment and while detained in hospital?**

Ferns (2005:138) confirms “power is always present in any interaction between practitioner and service users”. The *National Service Framework for Older People* (2001) emphasised the importance of advancing the social inclusion of older people through their empowerment and involvement. The ability to process information can slow with age, so older people should be given plenty of time and opportunity to ask questions during their assessment but several stated they were not involved at the time of their assessment. Harry and Michael’s experience of assessment suggested that some professionals marginalised them and their families during the process which is tantamount to their exclusion and led to them feeling disempowered. Harry said, ‘nobody listens’ while Michael commented ‘you have no say’.

The language used during the assessment may be part of the problem. During my interviews with professionals, older people and caregivers, their individual perspectives were often expressed through different vocabularies possibly reflecting the inequality of knowledge held by participants. If inappropriate language is used by professionals at the time of assessment, this may make understanding difficult for both the older person and the caregiver. Rogers and Pilgrim (2003) comment, service users are arguably disempowered by the type of knowledge differential that is common to all interactions between experts and non-experts. Giving equal value to both types of knowledge could help facilitate the assessment process, while a positive professional attitude towards active family

involvement may also act as a facilitating factor. However, according to Harry's daughters and Valerie's husband, the sharing of knowledge was not, at times, a common occurrence.

Relationships between caregivers and professionals are not always straightforward at the time of assessment because some families are excluded as a result of poor communication which is evident within Harry's, Valerie's and Katherine's stories. Caregivers have a unique relationship with the older person and professionals should use them as a source of information. Edward's experience lends support to the development of mental health services where the professional, older person and family caregiver relationship was central to a successful outcome. However, the opposite was true with John where professionals did not use the experiential knowledge held by both the older person and his caregiver – which led to John initially receiving the wrong treatment and being in hospital a lot longer than was necessary. John's wife advised them that on previous occasions John had required ECT – but they did not listen and made a decision to prescribe medication which did not have the desired effect and only then decided to give John ECT. The decision was taken regardless of what the family thought or advised. This suggests that the best results may be achieved using a broad collaborative approach to care provision where all views and wishes are not only considered and acknowledged but acted on. Concern was expressed within an Audit Commission (2006a) report on mental health services in older age highlighting the limited involvement of older people within mental health services in the assessment and planning of their care,

because of a total “lack of consultation” with professionals. If older people and their families are not consulted and so empowered at the time of assessment, alternatives to detention may remain just that - alternatives.

### **3) What are the outcomes for older people following discharge from hospital?**

Relationships between older people and their caregivers are not always positive, and occasionally there are emotional conflicts of interest between the caregiver's wishes and the older person's best interests. at the time of discharge. Some older people, for example Charlotte, Michael and Joseph wanted to return home but both professionals and families decided they needed supported care, which implicitly suggests they were not capable of returning home to live independently as they had prior to admission. It could be argued that the efficacy of the compulsory detention of older people should be judged by its outcomes and should not be considered effective unless the older person and their respective caregivers agree with the decision. It will not always be easy to gauge satisfaction, partly for methodological reasons and partly because older people may be reluctant to voice reservations or criticism of the support they received, or indeed of the people who delivered it. However, consideration should be given to whose perspective relating to the efficacy of detention is being considered. An older person may only consider the outcome as positive if they are allowed to return home following discharge from hospital, but this may not always be possible because of the continuing care requirement related to their ongoing mental distress. Alternatively, from a professional perspective, they may have no option but to discharge the older

person to a nursing home because of the requirement for ongoing care and in turn, may view this outcome as positive.

According to Brannelly (2006) satisfaction should not be the only consideration when determining the efficacy of detention and the relevant outcome suggesting that when care package arrangements are negotiated at a pace that allows the person to participate, the outcome is one of acceptance rather than rejection of the proposed care arrangements which suggests that arguably, what matters is the pace, rather than the package. Harry's family were not involved in discharge arrangements and were unhappy a suitable care plan had not been put in place only receiving a last minute phone call informing them their father was returning home – not a pace that suited Harry's wife or his daughters. Charlotte was not pleased about not being allowed to return home and Michael could not understand why he was still in hospital although he had been discharged from his section – neither was involved in discharge discussions.

On discharge, Harry's mental state was described as stable and although there had been an improvement in Charlotte and Michael's mental state, both were not allowed to return home, where they were admitted from. In order to reach suitable outcomes, it may be necessary for professionals to have an awareness of the older person's biography as described by Kitwood (1997) that acknowledges the wishes of both the older person and their caregiver, progressing at a pace to suit everyone to ensure an acceptable outcome. If discharge is to be to a nursing home, then the

older person may be more accepting if the reason why the decision was made is explained to them at a pace they can fully understand.

It may be too simplistic to assess the efficacy of detention purely in numerical terms rather than nature, but if the factors that led to the detention of the older person had been addressed during detention, then why was the decision made to discharge them into care? Although admission to care may be seen as a positive outcome in some circumstances, it is the case that Charlotte, Michael and Joseph all wanted to return to their own homes, but caregivers and professionals agreed discharge to a care home would be in the older person's `best interest`. Although an improvement in Joseph's mental state had been reported, there were ongoing concerns with non-compliance. Harry, Josephine and their families were often critical, expressing a need to be listened to and to have their views respected and consequently, wanted to have some choice and control over their individual care package arrangements at the time of discharge. This would suggest that the care package process is as important to the older person and their caregivers as the eventual outcome. To create an environment where `care` actually works will require informed consultation with the older person and their caregiver, because arguably, it is their right to choose although capacity will be a key factor during this process. At the time of discharge from hospital, the importance of a holistic assessment of the older person's social circumstances cannot be over-emphasised. The majority of older people within this study (73%) lived in their own home and so with a suitable care package, then consideration should have been

given to providing care within their own home. However, family commitments, for example, where they live, may ultimately dictate if they are able to meet the demands that undoubtedly accompany the caregiving process.

Although a certain amount of risk is involved, the focus should be on managing the delicate balance between the independence and protection of the older person. The complexity of successfully managing risk as a key determinant in the effective aftercare of older people following discharge is acknowledged. However, it is the ability to address the complexity of needs while assessing the balance of risk and, the adoption of a fully inclusive holistic approach to the assessment of older people's needs that may provide the foundation for quality aftercare and will ultimately define the efficacy of detention. John's experience provides a good example of the need to balance the risk. John was non-compliant with medication prior to his assessment and it was considered this may have contributed to his mental distress. On discharge, John was allowed to return home to his wife who, according to the professionals, had a known alcohol problem and had in the past, and was expected to continue, monitoring his medication. At this particular time, John may feel he is capable of controlling his own medication while his wife will be aware that his non-compliance may again result in John's re-admission to hospital. Hence a risk exists that needs to be balanced.



**4) What is the `lived` experience of compulsory detention for older people, their families and professionals?**

**The Older Person's Experience - A Lifecourse Perspective.**

A lifecourse approach emphasises the importance of seeing older people in the context of their life history. Biographical approaches to work with older people stress the importance of individual life stories and include activities such as reminiscence, storytelling and life review work. No Health without Mental Health (2011) – the Government's strategy framework for mental health takes a life course approach to mental health, spanning children and young people's mental health issues through to very old age. The strategy is based on six shared objectives, developed with partners from across the mental health sector, and focus on 'Recovery' and the reduction of stigma and discrimination as overarching themes.

What Michael and Charlotte's experiences have in common is that they unfolded over time across multiple generations. Charlotte's son Steven said there had been `trouble` in their house for as long as he could remember – his mother and father arguing continually which resulted in him and his two brothers being taken into care. This led to the total break down of the whole family which may have been the start of Charlotte's psychological problems, the stress and anguish of losing her family, her children at such a young age. The lifecourse perspective emphasises the ways in which relationships both support and control an individual's behaviour. Relationships can control behaviour through expectations, rewards, and punishments. If Charlotte had developed good relationships with her sons at a very early stage, she could have expected to be rewarded by seeing her children and

grandchildren grow up and so pass through their respective life stages – instead it appears she may have been punished for her behaviour. Michael's life from an early age was one of isolation and exclusion although it may have been self inflicted. He was described by his sister as always being 'a loner'. Addressing social isolation is important at all stages of life, as social patterns are developed and maintained throughout the lifecourse. The cumulative impacts of isolation can be greater however, as people age and as opportunities for social engagement become less frequent due to factors such as poor health and loss of mobility. Clarke *et al* (2003) insist life story work helps practitioners understand the needs of service users better and form closer relationships with them and their families. Any aspirations for a new strategy need to be considered in the context of current financial constraints. However, there are also considerable costs of treating poor mental health and wellbeing across the lifecourse and may far outstrip the investment needed, even though this might not be immediately evident.

There are several similarities in Charlotte and Michael's experiences – both had a physical disability and both lived alone with little if any community contact. Given the potential adverse impacts of social isolation on the mental health of older people future initiatives should consider supporting and increasing service delivery of community programmes. It is important to increase community awareness of services for older people and monitoring those that utilise the provided services and those that do not. A system that seeks to engage older people and their communities to make them healthier and safer by creating policies, services and

structures designed to support and enable active ageing and continued participation in society will show rewards in the long-term. Interventions may be effective in reducing social isolation among older people and so by extension keep them out of hospital. However, the impact of these interventions and the possible health and social outcomes may require more in-depth empirical research to develop and evaluate interventions that can be effective in this area.

### **The Caregiver Experience.**

As mentioned previously, the caregiving experience will start well in advance of assessment and admission to hospital. However, the process of discharge is undoubtedly a complicated one for the older person, the professionals but arguably, mainly, for the family caregivers. Caregiving for an older person with a diagnosed mental disorder will often require many more skills than looking after an older person with a physical disorder. Nevertheless, Harry's daughters stated they simply 'received a phone call' telling them their father was being discharged. They were both office workers with no experience of caregiving for an older person with a mental illness but their lives were about to change. Day-to-day frustrations, for example in Valerie's story, such as endless repetition, continually walking around, or being unable to encourage Valerie to complete the simplest task, had a serious cumulative effect on her husband's ability to cope. He was a retired factory worker, again with no experience, but he willingly undertook the role.

Caregivers need to feel part of a supportive team with ready access to up-to date information which will be as important to them as it is to the professionals. They are

now the main caregivers and their role is a vital one. Caregiving tasks can involve physical and emotional care, or taking responsibility for someone's safety or well being. Before Harry and Valerie were assessed and admitted to hospital the lives of their respective families had changed but it got to the point where the care they were providing was not enough. At this stage it was too late – a crisis point had been reached. Some families within this study delayed when on a daily basis they witnessed a family member's behaviour gradually deteriorating. It can be a major responsibility to care for someone suffering from a mental illness, the emotional and behavioural components of some illnesses can be very difficult at times and many people do not seek out help.

Families may also have little knowledge about mental illness. For example, recognising depression in older people is not always easy. It is often difficult for a depressed older person to describe how he or she is feeling. Even when all members of the family have the knowledge to deal with mental illness, they may be reluctant to discuss their family member with others because they do not know how people will react. After all, myths and misconception surround mental illness. For many, even their closest friends may not understand. In Harry's case his family and friends stayed away because of his behaviour. Caregivers may be particularly sensitive to the views or presumed views of relatives and friends about mental health problems and this can be a factor in their willingness to disclose their own problems or to seek professional help.

Caregivers need some direction accompanied by a sense of hope that recovery is possible – a feeling that they are not on their own and that their efforts will be rewarded. As Wallcraft (2002) concludes, recovery can never be imposed on a person, but for many, the belief that recovery is possible can provide the hope and motivation to take the first step. They may feel that mental illness is a `life sentence` but they need to know that with medication, psychotherapy or a combination of both, the majority of people do return to a normal life style. It is also imperative that the family finds sources of ongoing support for themselves that helps them care for the older person who is recovering or working towards recovery so they can integrate into society and lead fulfilling lives.

### **The Professional Experience.**

As the population continues to age, professionals are faced with increasing demands and consequently, understanding their experience is pivotal in the design of effective support services for both older people and their families. It may become a challenge, and at times, it may be extremely stressful as reported within Harry's, Michael's, Charlotte's, Josephine's, Valerie's and Joseph's experience. Some professionals will tend to draw upon their own experiences when assessing and treating older people. In many specialist mental health services, those who recover quickly are discharged from care and so, over time, professionals tend to accumulate most of their experience in trying to treat those who do not fully recover or who recover and then relapse. They may not have the time to keep in touch with those who recover and stay well to enquire about their life-style and so determine

those important factors that may have kept them well which could then be applied to practice – but arguably they should if it is going to improve treatment and outcomes for older people.

Professionals use a mix of treatment options, including medications and psychotherapy, depending on the mental illness. All older people within this study were prescribed and given medication on arrival on the ward. Possibly there is an argument for medication not being a first line intervention or sole intervention in symptoms where non-intrusive interventions are available and have demonstrated the same level or better efficacy. When I spent time at the Queen Elizabeth Psychiatric Hospital, I spoke to a senior ward nurse and asked what his priorities were when a `new` patient came into hospital. He replied without hesitation, `get them on the ward and get the meds into them`. I had similar comments from other staff which is the reason for my suggestion within my reflexivity chapter to include ward staff in the interview process in any future research – they are `front-line` staff. Out of the 15 older people who took part in this study, only 2 (13%) were fully compliant with their medication – the remainder had refused any offers of help or treatment, would not take their medication prior to admission, and when admitted they still refused. This should compute with the reason that patient compliance is so universally criticised. The "cure" is often worse than the "disease" in psychiatric parlance. When people are given medications which not only fail to adequately mask the symptoms they are prescribed for but also add new distressing and often

permanent effects, an argument could be leveled at some professionals for simply acting in the interests of their own self-preservation.

From my observations within this study professionals are in an undoubted position of power. They have been given the authority to protect both the older person and the general public through the use of mental health legislation if necessary, but how does this situation manifest itself? Most older people within this study resisted contact with services and were finally pressured into it by others, particularly family members. They had lost their independence and so their position had become weaker. Although they may have tried, they could not solve their problems possibly because, according to professionals, they were in denial, afraid of what the consequences may hold. Their feeling of helplessness will have been even stronger in a society that values competence, self-reliance, and responsibility and so the relationship with the professionals begins with an inequality of power. Professionals, as experts, are strong – but it has been argued earlier that the older person may be the expert because of their experiential knowledge. The older person felt weak and powerless because they were now dependent on the professionals for a diagnosis and treatment. At the beginning of the contact between professionals and the older person there was a clear imbalance. The former were independent and competent while the latter were dependent and incompetent.

It is of utmost importance professionals recognise and acknowledge this imbalance of power in this relationship, not to make it any larger than it already is, and to

reduce it as much as possible. The imbalance of power can be limited by being aware of it - it is better to realise that this imbalance exists than to try to instil all sorts of manipulations in the hope of being able to eliminate it. Enlarging the older person's competence by increasing their knowledge can diminish dependence and powerlessness. Professionals should endeavour to increase their older person's ability to solve their own problems through education - teaching them and their families the necessary skills to help recognise symptoms at an early stage, avoiding reaching crisis point which would increase the possibility of hospital admission. It is important that professionals fulfil their duty of care by advising, supporting and assisting families. However, sometimes they may rely on caregivers to tell them what they need and how they want them to help – that is the time to listen. Trust, inclusion, acceptance and good communication is essential in good care and must be developed between professionals and caregivers. The different problems faced by each need to be understood before mutual respect and trust can grow. Professionals can play a critical role in identifying resources in the community that can help the family build the knowledge base that will give them the tools to assist the older person to recover and so by extension, keep them out of hospital. As Barnes (2006) suggests, there are particular professional skills as well as knowledge that lay-caregivers and those they support can benefit from and have a right to expect.



### **Research Findings.**

Several findings have confirmed previous findings, including the overrepresentation of women using mental health services (Barnes *et al* 1990, Hatfield and Mohamad 1994, Rogers and Pilgrim 2003) The use of Section 2 of the MHA (1983) was again the principal mechanism used to initiate compulsory detention (Gilmore *et al* 1994, Feehan 1994). Wallcraft (2002) and Jones (2002) report the importance of including caregivers in the care process and not excluding them – a point confirmed within this study by different family members (Harry, Josephine, Valerie).

### **New Findings – Contribution to Knowledge.**

To fully realise the importance of my research findings this study will need to be put in context. Many of the themes emerging from this study have been found in previous studies but there is one very important difference – none focused specifically on the experience of older people who had been compulsorily detained under the Mental Health Act (1983) This in itself is new knowledge. There have been previous studies (Rogers *et al* 1993, Barnes *et al* 2000, Barnes 2006) that have successfully drawn on the perspectives of service users, but not specifically of older people. Furthermore, the use of one-to-one narrative interviews, adopting triangulation as a method to improve validity and the use of Interpretative Phenomenological Analysis (IPA) for analysis within a study specifically focused on the use of the MHA (1983) with older people is new knowledge. There have been themes identified in previous studies, but within a different context. Consequently, the new knowledge reported within this study is -

- Ageism within mental health services has been identified within the context of this study. Just 13% of older people received an assessment at home and consequently confirms findings in a previous study by the Royal College of Psychiatrists (2009) They found that if a person under 65 has a crisis at home, they can receive immediate assessment and treatment at home from a 24-hour specialist team – if you are over 65 you cannot. However, my study also extends previous analysis by reporting that all older people were compulsorily detained in hospital following their assessment.
- One third of older people, *65 and over*, within this study were aggressive prior to assessment and almost a half were angry and shouting which develops existing understanding reported by Zarit *et al* (1986) that psychotic symptoms across *all age groups* can be associated with aggressive or disruptive behaviour and often result in institutionalisation.
- Power inequalities and lack of inclusion in care plans has resulted in disengagement of older people from mental health services. Fifty-three per cent of older people stated they had problems relating to communication and treatment during their stay in hospital. Harry, Charlotte, Michael, George, Joseph all said that because of the way they were treated, they would not contact services again in the future. This finding contributes new insights into studies by Campbell, (1989) Jones (2002) and Wallcraft,

(2002) who emphasised the importance of good quality relationships between people with mental illness, families and professionals.

- Some older people are incorrectly prescribed medication that does not meet their needs because they are not involved in discussions relating to their care and treatment at the time of assessment. All 15 older people within this study were initially treated with medication. Harry, Michael and John, all believed they did not need medication. In John's case in particular, this was eventually accepted by professionals who then prescribed ECT.

The themes identified are important because they not only capture the essence of the participants experience, they are critical to the care of older people with mental distress. Consequently mental health workers will need to be mindful when dealing with older people and their families who are faced with a mental health crisis.

### **Recommendations for Future Research.**

This study highlights several areas where further research may prove beneficial to service users, caregivers and professionals. Hence, I would recommend:

- Further investigation to determine the level of communication between professionals, older people and families at the time of assessment, treatment and discharge, to help identify possible areas of exclusion throughout the process.
- A longitudinal study that explores not simply where older people are discharged to from hospital, but more importantly, an investigation into the long-term outcomes, including whether the older person re-enters hospital, or remains in the community.
- An examination of what older people and caregivers believe is effective in terms of the range of services available and also explore how best these can be delivered in order to lead to improved outcomes for both.

- A longitudinal research study that explores the impact of caregiving on the caregiver and also the impact of new policies and legislation.
- A study exploring the different elements of care to assess their relative effectiveness, while also seeking to identify whether there is any `added value` for caregivers.

Mental health research has the important function of exploring, developing and in turn reporting the knowledge required to continually help improve the mental health and well being of the general population, including that of older people. However, it is the case that the considerable achievements are often insufficiently followed through with the necessary implementation and integration into practice as reported in chapter two (Help the Aged Report, 2006) I acknowledge person-centred care was not the direct result of a research study but the approach does lie at the heart of the *National Service Framework for Older People* (2001). Hutton (1999) states that central to its success, will be staff who possess the necessary knowledge, skills and competencies to care for older people. However, this study has demonstrated that person - centred care has not always been at the forefront of care for older people. To actively promote mental health in old age, we need to understand how older people live, what their social networks are, what their wishes are and how they are treated by society. Most of that type of data is anecdotal and yet, there has been no systematic account, until now, that explores older peoples` experiences relating to their mental illness. To an extent, this may be connected to the attitude of some researchers who may view older people with a mental illness as `unreliable` sources of information. Hence, a further recommendation that could

have been made is that information about the experience of older people who have had a mental illness and subsequently been detained in hospital, should be more systematically recorded and used, for example, in anti-discrimination and anti-stigma activities which would raise much more awareness of the phenomenon under study among society. Focusing on known risk factors and providing support where required can effectively promote mental health in later life at individual, social and societal levels, with multi-professional work essential in meeting this aim. As explained in the introduction, this research study was aimed specifically at exploring the experience of older people who became subject to compulsory detention under the MHA (1983) It is hoped that the framework I have presented related to the use of the MHA (1983) with older people, incomplete and emerging as it is, will help to realise not only this aim, but more importantly stimulate debate and so promote genuine partnerships between all those involved in addressing the needs of an ageing society, particularly those older people with a mental illness.

### **Limitations to the Study.**

My study does have several limitations. Firstly, unpublished studies by researchers who have not yet published their findings about older people and the impact of the MHA (1983) may be under-represented. In relation to the adopted methodology, because my case studies deal with only one group, that is older people, we can never be sure whether conclusions drawn from this particular population apply elsewhere. The results of the study are not generalisable because we can never know whether the cases we have investigated are representative of the wider body

of "similar" instances – for example with people under the age of 65. Additionally, the study would be difficult to replicate in its entirety, because the social circumstances of the older people may be completely different to those who took part in this study. As mentioned earlier, case studies involving one-to-one interviews are highly time consuming which prevented me from interviewing some older people for a second time, particularly those whose `voice` was not so strong during the first interview. Finally, because case studies are based on the analysis of qualitative data a lot depends on the researcher's interpretation of the data that has been gathered. This means that there is a lot of scope for researcher bias and it could be that the subjective description and interpretation may differ between researchers – the data may be analysed differently. Interpreting the data means the researcher decides what to include or leave out.

## **APPENDIX 1.**

### **Relevant Sections of the Mental Health Act (1983) Referred to Within this Thesis.**

- **Section 2.**

This is the most common method for detaining people. It allows for a person to be detained in hospital for assessment, followed by treatment if necessary for a period of up to 28 days. It cannot be renewed, but if a person required further treatment, a Section 3 (below) can be implemented. The grounds for the application are that the person is, *“suffering from a mental disorder of a nature or degree which warrants the detention of the patient in a hospital for assessment (or for assessment followed by medical treatment), and he should be detained in the interests of his/her own health or safety, or with a view to the protection of others.*

- **Section 3.**

This is a compulsory admission for assessment and treatment for an initial period of 6 months, which can be renewed for a further period of 6 months, and then if necessary, can be renewed for further 12-month periods. Applications must be based on two medical recommendations, preferably one of the doctors should have prior knowledge of the patient. The two doctors should have assessed the patient within five days of each other, and need to be in agreement regarding the reasons for detention. Under the Act, an approved social worker is also required to agree that detention is necessary. Similar grounds apply as above in Section 2, but treatment must be necessary for the health and welfare of the person.

- **Section 4.**

Allows for compulsory admission to hospital in cases of emergency. It can be used in place of a Section 2 where there is extreme urgency, and where the delay in implementing a Section 2 is not acceptable (the Act refers to “undesirable delay”). A recommendation by one doctor who knows the patient is required, or who has been approved under Section 12 of the Act. The section can last for up to 72 hours, but during this time, if a second medical recommendation is made, it can be converted to a Section 2. A Section 4 cannot be extended, and cannot be converted to a Section 3. A Section 2 gives the patient no rights of appeal, and a nearest relative cannot apply for discharge.

- **Section 5 - (2) (4)**

This section allows for an informal patient being treated for a mental disorder to be held in hospital, where there is a possibility they may leave before an application under Section 2 or 3 can be made. It should only be used in cases of emergency to give time for a section 2 or 3 to be made. Application under this section can be made by a doctor under Section 5(2), and can last up to a period of 72 hours, or by senior nursing staff under a Section 5(4), which last for 6 hours or until a doctor arrives. If a doctor decides to apply a Section 5(2) after a nurse has applied a Section 5(4), the 6 hours of the nurse's order are included in the 72 hours. The patient can only be discharged by the Responsible Medical Officer, and has no right of appeal.

- **Section 135 and 136.**

Section 135 allows an officer to enter locked premises to search for a person they have reason to believe is mentally disordered, and also that the person is in need of care. A doctor and an approved social worker must assess the person when they arrive at the place of safety. If they do not see the person at the same time, and the doctor has decided the person does not require to be admitted to hospital, the approved social worker must still see the person.

Section 136 allows for a police officer to remove a person to "a place of safety", where the officer decides the person is suffering from a mental disorder, and may be a danger to himself or others. The officer need not suspect a criminal offence has been committed. A place of safety can be a police station or a hospital, and the person can be detained for up to 72 hours.



## **APPENDIX 2.**

### **LETTER OF INVITATION TO FAMILY MEMBERS.** **CIRCUMSTANCES IN WHICH OLDER PEOPLE ARE DETAINED.**

Dear NAME,

During the next 12-month period I will be conducting interviews with people who have had a family member compulsorily detained under the 1983 Mental Health Act.

My intention is to explore peoples` experiences of detention, including their social circumstances before assessment and after discharge. I am interested in finding out how detention impacted, not only on their life, but also on members of their family.

As you may be aware, the 1983 Mental Health Act is currently under review, and it is possible there will be some change in the law. However, at this present time, I am unaware of any specific research that focuses on the experiences of older people who are, or have been subject to compulsory detention.

I work in the Institute of Applied Social Studies at the University of Birmingham, and have a genuine interest and commitment to research which focuses on peoples experiences of compulsory detention. Would you be prepared to speak to me, at a time and place convenient for yourself, about your experiences of NAME being detained under the 1983 Mental Health Act.

If you would agree to take part in this study, would you please fill in the attached slip, so I can contact you. The interview will take approximately twenty minutes, but please note, that if at any time you would like to stop the interview you can do so. Results will be written up so that it will not be possible to identify any particular participants.

Thank you for taking the time to read this letter.

Best Wishes,

Yours sincerely,

Mr Larry Ball.

### **APPENDIX 3.**

#### **INFORMATION SHEET FOR OLDER PEOPLE.**

##### **TITLE OF STUDY.**

##### **CIRCUMSTANCES IN WHICH OLDER PEOPLE ARE DETAINED.**

Dear NAME,

I am writing to you because you have been in hospital under a section of the 1983 Mental Health Act; this is sometimes called being “sectioned”. Would you be prepared to speak to me, at a time and place convenient for yourself about your experiences of being detained under the 1983 Mental Health Act?

##### **WHAT IS THE STUDY ABOUT?**

The study will focus on the circumstances in which older people are compulsorily detained under the 1983 Mental Health Act. It will also explore the reasons why this is considered the appropriate action, and the impact of this on older people and their families (if relevant).

##### **WHAT WILL I HAVE TO DO AND WHAT IF I DO NOT WANT TO TAKE PART?**

It is important to inform you that the information will remain anonymous. If you do decide to take part in the study, your name will not appear within the study at all. I do hope you will agree to talk to me. I enclose a slip you can return to me to let me know, and I will then contact you to arrange a time to meet up. If you do not want to take part in the study, do not fill in the attached consent form, and do not return it.

##### **WHAT ARE THE BENEFITS AND THE RISKS INVOLVED WITH THE RESEARCH?**

Hopefully the research findings will contribute to improved assessment procedures, and an increased understanding of the impact of compulsory detentions, on both older people and their families. The only risk is that you may find it upsetting talking about your assessment/detention experience. However, many people often welcome the opportunity to talk about what has happened to them, and I have a lot of experience of working with people who have been detained in hospital.

### **WHAT WILL HAPPEN TO THE INFORMATION?**

The information received will contribute towards an academic qualification, ie PhD, which the researcher is studying for at the University of Birmingham. It will be available for reading by students and staff at the university library, and it is expected that sections of the study will be published in professional journals, and sincerely hope that it will be used during the training of doctors and social workers.

### **WHO ELSE IS TAKING PART?**

It is my intention to interview 60 (Sixty) people in total, made up of 15 service users, 15 family members, 15 doctors and 15 Approved Social Workers.

### **WHAT HAPPENS IF I DO NOT UNDERSTAND SOMETHING?**

That will not be a problem, you can discuss any questions with your researcher, you can ask questions if you so wish, and you can stop the interview at any time that suits you.

### **WHAT HAPPENS AT THE END OF THE STUDY?**

At the end of the study, the research findings/analysis will form part of a thesis leading to a PhD degree. Please remember that the information contained in the study will be anonymous, so there will be no means of identification. All records will be destroyed.

### **WHAT HAPPENS IF I CHANGE MY MIND DURING THE STUDY?**

If it is your wish to withdraw from the study, then that will be honoured at any time.

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#### **APPENDIX 4.**

PLEASE RETURN THIS TO LARRY BALL IN THE ENVELOPE PROVIDED- IT DOES NOT REQUIRE A STAMP.

#### **CONSENT FORM.**

**CIRCUMSTANCES IN WHICH OLDER PEOPLE ARE COMPULSORILY DETAINED.**  
**AT THIS POINT I WOULD LIKE TO CONFIRM THAT IT IS THE RESEARCHER'S INTENTION**  
**TO INVITE DOCTORS, ASWs AND FAMILY MEMBERS(IF RELEVANT) TO TAKE PART IN THE**  
**STUDY AND COMMENT ON THE MENTAL, PHYSICAL AND SOCIAL CIRCUMSTANCES OF**  
**THE OLDER PERSON AT THE TIME OF ASSESSMENT/DETENTION.**

Yes, I am prepared to be interviewed for this project.

My name is.....SIGNATURE-.....

In order to arrange a convenient time for interview,

Please phone me on, (your phone number).....

Or write to me at, (your address).....

.....

.....

.....

or E-Mail me at, ( your E-Mail address).....

I would like to assure you of complete confidentiality throughout this study. If at any time you request feedback, it will be made readily available to you by myself, Mr Larry Ball the chief investigator You can contact me in any way that suits you, using any of the contact details provided in the information sheet.

## **APPENDIX 6.**

### **TRANSCRIPTION. (Harry`s Story)(Name changed for confidentiality)**

**I** - How did you feel before your assessment?

**R** - There was nothing wrong, but I had to `go in and get my head done` - I was abusing my wife, well not abusing, I have never abused anyone in my life - we were disagreeing all the time, arguing over this certain third party, who I think er, (long pause) she should have nothing to do with, they said it was all fantasy

**I** - Can you tell me about your assessment?

**R** - It took place here in my flat. I went from here to the Q.E. - the er, (pause) hospital in an ambulance, they made me go - there were questions, I didn`t know what they were talking about, next thing I`m in an ambulance, and er (hesitating) off to the QE

**I** - What happened when you arrived at the QE?

**R** - I had been in Selly Oak first, then went home, then all hell broke loose, a right `hullabaloo`, I was told I was going to the QE - but I was just left, no one spoke to me I wanted to come home, but they, er, (thinking) would not let me,

**I** - How were you treated in hospital?

**R** - I saw a doctor, I think he was a consultant and he examined me, but I don`t know why I was in there, (rather loud) there was nothing wrong - I shared a room with four other people during the day, one, er, er, coloured guy, there was nowhere to go,

**I** - How did you get on with the other patients on the ward?

**R** - Got on my nerves a bit, spoke to me now and again, passes the time but I er, (sigh) just kept to myself, that`s best I think

**I** - What about the staff on the ward?

**R** - Some were difficult to, er get on with you know, to talk to, they helped if you asked, otherwise they left you alone, and the doctors, (laughing) they were a waste of time, I kept telling them I was OK, but they wouldn`t listen - kept giving me tablets

**I** - What happened at the end of your stay in hospital?

**R** - I was told I was going home, I, er, was told I was finished and that was it (pause, thinking) er, my wife was here, my daughters came around – they took care of me - since my wife died I get the er, meals at dinner time, the girl brings them

**I** - Do you feel the treatment you received in hospital helped?

**R** - No, there was nothing wrong with me, my, er, girls told me I was bad and I had to behave myself, I had never been bad before, always talking about my head but I didn't feel well - it was all the tablets they gave me (long pause) – they made me feel worse

**I** - Why was that do you think?

**R** - I was on the wrong medication, I kept telling them, but nobody listened

*At this time we had a pause, there was a knock at the front door which I answered, Harry has mobility problems, it was the lady from social services with his lunch time meal. I let Harry have his lunch and we had a cup of tea before continuing with the interview.*

**I** - How have these events impacted on your family?

**R** - My wife has died now, my daughters have been upset, but I think it was down to them I ended up in hospital. There was something going on, I don't know what but they had something to do with it, me going in hospital (fairly loud)

**I** - If you felt unwell in the future, would you go into hospital again?

**R** - No, I would never go near them again, I was OK before I went in, nothing wrong with me, but when I came out, oh God, I was terrible, no never again

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